

Running head: TREATING OCD IN CHILDREN WITH PDD

Using Function-Based CBT with Parent Involvement to Treat OCD in Two School-Age Children  
with High-Functioning Autism

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## Abstract

Obsessive Compulsive Disorder (OCD) involves excessive worry coupled with engaging in rituals that are believed to help alleviate the worry. Pervasive Developmental Disorders (PDDs) are characterized by impairments in social interaction, communication, and the presence of repetitive and/or restrictive behaviours (American Psychiatric Association, 2000). Research suggests that as many as 81% of children with a PDD also meet criteria for a diagnosis of OCD. Currently, only a handful of studies have investigated the use of Cognitive Behavioural Therapy (CBT) in treating OCD in children with autism (Reaven & Hepburn, 2003; Sze & Wood, 2007; Lehmkuhl, Storch, Bodfish & Geffken, 2008). In these case studies, the use of a multi-modal CBT treatment package was successful in alleviating OCD behaviours.

The current study used function-based CBT with parent involvement and behavioural supplements to treat 2 children with PDD and OCD. Using a multiple baseline design across behaviours and participants, parents reported that their child's anxiety was alleviated and these gains were maintained at 6-month follow-up. According to results of the Children's Yale-Brown Obsessive Compulsive Scale (Goodman, Price, Rasmussen, Riddle, & Rapoport, 1986) from pre- to post-test, OCD behaviours of the children decreased from the severe to the mild range. In addition, the parents rated the family's level of interference related to their child's OCD as substantially lower. Last, the CBT treatment received high ratings of consumer satisfaction.

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## Using Function-Based CBT with Parent Involvement to Treat OCD in Two School-Age Children with High-Functioning Autism

Pervasive Developmental Disorder (PDD) is an umbrella term used to refer to five disorders on the autism spectrum. These disorders include Autistic Disorder (AD), Asperger's Syndrome (AS), Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Rett's Disorder and Childhood Disintegrative Disorder (DSM-IV-TR; APA, 2000). Filipek et al. (1999) referred to PDDs as "a wide continuum of associated cognitive and neuro-developmental disorders, including, but not limited to, three defining features: impairments in socialization, impairments in verbal and nonverbal communication, and restricted and repetitive patterns of behaviour" (p. 439). The prevalence of PDDs is increasing steadily. The most recent epidemiological estimates report that PDDs are present in at least 60 out of 10,000 children, or 0.6% of all children (Fombonne, 2005). In comparing PDDs to other challenges, prevalence rates are higher than those reported for childhood cancer, diabetes, spina bifida and Down syndrome (Filipek et al.). Besides the challenges related to having a PDD, these children often have co-morbid diagnoses, such as Obsessive Compulsive Disorder (OCD). Although preliminary, studies report that children who are high functioning, those generally described as being verbally fluent and having at least a Borderline IQ, are at increased risk for OCD in comparison to clinic and nonclinic child populations (e.g., Gilliott, Furniss & Walter, 2001; Gadow, Devincent, Pomeroy & Azizian 2005). The current study evaluated the use of Cognitive Behavioural Therapy (CBT) for OCD in two school-age children with High-Functioning Autism.

### *High Functioning PDDs*

Children presenting with PDD represent a heterogeneous population. Given this fact, in recent years, there has been an attempt to differentiate between individuals with High

Functioning Autism and Low Functioning Autism. Although not officially stated in the DSM-IV-TR (APA), several researchers are using a set of criteria to separate high and low functioning autism. Typically, High-Functioning Autism (HFA) is used to describe individuals who have an IQ above 69 and are verbally fluent (Thede & Coolidge, 2007).

#### *Reasons to Focus on HFA*

This study focused on treating children with HFA for a number of reasons. Researchers have acknowledged the vulnerability of individuals with HFA to OCD, with evidence suggesting that children with HFA are at increased risk for OCD in comparison to community and clinical samples including children with Low Functioning Autism but exact estimates are unknown (Gadow et al., 2005). According to Leyfer et al. (2006), up to 81% of children with PDD present with this dual diagnosis. As well, CBT has shown considerable promise with typical children with OCD. Given that many children with HFA have similar cognitive and adaptive functioning levels, it may also prove to be a useful treatment for children with HFA. In fact, three preliminary case studies ( $N = 1$ ) (Reaven & Hepburn, 2003; Sze & Wood, 2007; Lehmkuhl, Storch, Bodfish & Geffken, 2008) and one randomized controlled trial (RCT) with eight participants with HFA receiving CBT for OCD (Wood et al., 2009) have shown success in alleviating obsessions and compulsions.

#### *Obsessive-Compulsive Disorder*

Obsessive Compulsive Disorder (OCD) is a chronic anxiety disorder. The DSM-IV-TR defines obsessions as recurrent and constant intrusive thoughts, impulses or images that cause excessive anxiety. Obsessions are more than extreme worrying about real-life problems and the individual attempts to ignore them or engage in some action to neutralize them (APA, 2000).

Compulsions are characterized as repetitive, avoidant or mental behaviours that the individual feels driven to perform in response to an obsession. The behaviour the individual engages in is aimed to reduce his or her anxiety or prevent some dreaded event from occurring. These behaviours are not, however, connected in any realistic way to the obsession they are designed to neutralize. For example, an individual may wash his hands for extended periods of time to neutralize his concerns about germs. To render a diagnosis, individuals recognize their obsessions or compulsions to be excessive and unreasonable. However, this egodystonic feature is not essential for a diagnosis of OCD, especially in children. Often, children have poor insight into why they may engage in certain behaviours. Nevertheless, the obsessions or compulsions must cause marked distress, be time consuming, and significantly interfere with the individual's daily living (APA, 2000).

### *OCD in Children*

The symptoms associated with OCD affect several facets of an individual's life at any age. In the majority of clinical cases of childhood OCD, individuals experience both obsessions and compulsions (Shafran, 2001). There is a growing body of research that points towards OCD having a bimodal onset, with the age of onset in children being 10 to 10.5 years, and a second age of onset for adults in the early 20s (APA, 2000). Research suggests that an earlier age of onset is associated with higher likelihood of OCD in the family of probands. As well the rate of first-degree relatives of children and adolescents with OCD who have the disorder (or a subclinical form) is higher than for adults (Shafran).

In addition to being co-morbid with autism, OCD is often found to be co-morbid with other disorders. Ivarsson, Melin and Wallin (2008) state that less than one in four OCD patients are free from co-morbidity. According to their study, boys with OCD were more likely to have

an accompanying neuropsychiatric disorder such as tics or Attention Deficient Hyperactivity Disorder. In contrast, girls with OCD were more likely to be dually diagnosed with Generalized Anxiety Disorder. In addition, when compared to a normative sample, children diagnosed with OCD showed higher levels of anxiety, aggression and depression.

### *Research into Childhood OCD in Typically Developing Populations*

In recent years, treatment studies for pediatric OCD in typically developing populations have become more common and investigations of the use of CBT have found it an efficacious treatment. A meta-analysis (Watson & Rees, 2008) on published randomized, controlled trials for the treatment of OCD in children was recently conducted. This comprehensive literature search covered pharmacotherapy and CBT treatments. Studies were only included in the analysis if they included participants aged 19 years and under with a primary diagnosis of OCD, employed randomization and a control condition as well as a reliable outcome measure. A total of 13 studies, five using CBT and the other eight using pharmacotherapy, met criteria and were used in the analysis. Both treatments were found to be significantly superior to controls. CBT had the largest treatment effect size ( $ES = 1.45$ ) and therefore, the authors concluded that CBT should comprise the first-line treatment for pediatric OCD, followed by pharmacotherapy ( $ES = .48$ ).

The Pediatric Obsessive Compulsive Disorder Treatment Study (POTS) was one RCT that was included in the meta-analysis. It was the first study to address pediatric OCD and directly compare the effects of an established medication, OCD-specific CBT, the combination of CBT and medication, and a placebo pill. The participants were 112 patients aged 7 to 17 years with a primary diagnosis of OCD. Any children with major depression, Tourette's syndrome or any PDD were excluded from the study (POTS, 2004). CBT treatment was based on the March

and Mulle (1998) manual and included awareness training, cognitive training, mapping of obsessions and compulsions, and graded exposure and response prevention (ERP). All patients were assessed at baseline as well as at 4, 8 and 12 weeks. Results indicated that patients treated with CBT alone (39.3% remission) or in combination with medication (53.6% remission) showed a substantial improvement in symptoms in comparison to the placebo control group (3.6% remission).

#### *Preliminary Research with Children with HFA and Anxiety*

*Treating anxiety in children with HFA.* Sofronoff, Attwood and Hinton (2005) evaluated the effectiveness of a brief CBT treatment for anxiety symptoms in children with AS. Participants included 71 children aged 10 to 12 years old. The CBT package taught participants effective coping mechanisms to manage their feelings and encourage them to broaden their emotional and behavioural repertoires. Families were randomly assigned to: (a) intervention one (child only); (b) intervention two (child and family); or a wait-list control group. CBT treatment consisted of six 2-hour sessions delivered to children in groups of three. Intervention two was offered in the same manner but also included a parent training component where parents were advised to encourage and coach their children in the use of coping strategies as well as completing their weekly homework assignments. Anxiety was rated by parents using the Spence Child Anxiety Scale – Parent (SCAS-P; Nauta et al., 2004), which includes situations that could provoke feelings of anxiety and has parents rate how applicable the feelings would be to their child. Results indicated that there was a significant difference in parents' ratings of their children's anxiety from the pre-test to 6-week follow-up for both the child only and child-parent intervention groups, with the parent training group showing more improvement than the child only and wait-list control groups (Sofronoff et al.).

Second, an RCT by Chalfant, Rapee and Carroll (2007) used family-based CBT to treat anxiety disorders in children with HFA. Participants were 47 children between the ages of 8 and 13 years who were randomly assigned to the CBT group ( $n = 28$ ) or a wait-list control group ( $n = 19$ ) that received treatment following a 7-month waiting period. All participants had an independent diagnosis of HFA and met criteria for at least one of the following: Separation Anxiety Disorder (SAD), Generalized Anxiety Disorder (GAD), Specific Phobia, Social Phobia or Panic Disorder according to the Anxiety Disorders Interview Schedule (ADIS; Silverman & Albano, 1996). The CBT was an adapted version of the “Cool Kids” program (Lyneham, Abbott, Wignall, & Rapee, 2003). This program included role-playing and having the children practice anxiety management procedures, cognitive therapy, relaxation sessions and exposures. Over 12 2-hour sessions, treatment was provided to the participants in groups of six to eight. Results indicated a significant decrease in the number of anxiety disorders at post-test for the children in the treatment group. Specifically, according to the ADIS (Silverman & Albano), 71.4% of the treated children no longer met criteria for any anxiety disorder at post-treatment. Also, parent-rated anxiety on the SCAS-P (Nauta et al., 2004) indicated a significant reduction in anxiety for the treatment group compared to the wait-list group. Therefore, the findings do provide preliminary evidence for the efficacy of CBT for the treatment of anxiety disorders in children with HFA (Chalfant et al.).

*Four studies focusing on children with HFA and OCD.* Reaven and Hepburn (2003) conducted the first case study that treated OCD in a child with a PDD. The participant was a highly gifted (IQ 135-145) 7-year-old girl who was diagnosed with AS. To determine the effectiveness of the treatment, this case study used parent ratings of OCD at pre- and post-treatment. In assessing her OC behaviours, her mother described that she had several urges

related to contamination, aggressive worries, and a 'need to know' obsession that interfered with the daily functioning of the participant and her family. A CBT protocol by March and Mulle (1998) originally designed for use with typical children was followed. Over approximately 6 months, the child was seen for a total of 14 sessions. To meet the needs of the child, the protocol was adapted to include her parents in an active role, visual strategies were used, and the child's interests were often incorporated into treatment. The Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS; Goodman, Price, Rasmussen, Riddle, & Rapoport, 1986) was used to assess the distress and interference the child experienced because of her obsessions and compulsions. From pre- to post-treatment, the participant's CY-BOCS score dropped to 8 (remission) from her original score of 23 (moderate), representing a 65% decrease in symptoms (Reaven & Hepburn).

Lehmkuhl and colleagues (2008) also conducted a pre-post case study that attempted to treat OCD in a 12-year-old male with HFA using the March and Mulle (1998) CBT treatment package. At age 11 years, the young boy (IQ 92) started exhibiting ritualistic and compulsive avoidant behaviours surrounding fears of contamination and sickness. He engaged in handwashing and repetitive checking that significantly interfered with his academic, social and family life. The child also compulsively avoided various stimuli by not sitting on chairs or using bed sheets, and refusing to touch items that he thought were dirty, such as public benches. The treatment provided consisted of 10 50-minute CBT sessions. Similar modifications to Reaven and Hepburn (2003) included having parents be an integral part of every treatment session, providing information to the teacher regarding the treatment so he or she could be more aware of the behaviours in school, and the cognitive component was adjusted to focus on identifying feelings of distress and learning coping statements. As well, a behaviour reward system was used

to increase the child's compliance during session and with the homework assignments. From pre- to post-treatment, the child's CY-BOCS score dropped from 18 (moderate) to sub-clinical levels (Lehmkuhl et al.).

A study by Sze and Wood (2007) investigated the use of a CBT program entitled "Building Confidence" (Wood, Piacentini, Southam-Gerow, Chu, & Sigman, 2006) to treat a range of anxieties in an 11-year-old girl with HFA. This case study used parent and child ratings of anxiety at pre- and post-treatment to determine the effectiveness of the treatment. According to the ADIS (Silverman & Albano, 1996), the participant met criteria for Separation Anxiety Disorder (SAD), Generalized Anxiety Disorder (GAD) and OCD. The participant's OCD symptoms included thoughts of hurting people, contamination worries, and a fear of losing possessions. She also engaged in checking and hoarding of worthless items. CBT was provided over 16 90-minute sessions. Similar to previously cited studies (Reaven & Hepburn, 2003; Lehmkuhl et al., 2008) the program was modified to include parent training and took into account the cognitive abilities of the participant. At post-treatment, the child no longer met criteria for any anxiety disorder according to the ADIS (Silverman & Albano). The treatment was also successful in developing the child's social skills, which allowed her to form friendships and improve her quality of life. This study illustrated the potential value of a multimodal CBT intervention with the appropriate modifications to meet the needs of a child with PDD (Sze & Wood).

Recently, a RCT was completed that treated anxiety in children who had HFA (Wood et al., 2009). Participants included 40 children aged 7 to 11 years diagnosed with HFA and one or more of the following anxiety disorders: Separation Anxiety Disorder (SAD), Social Phobia, or OCD. Similar to Sofronoff et al. (2005), a computer randomization program was used to



randomly assign participants to either immediate treatment ( $n = 17$ ) or wait-list control ( $n = 23$ ) conditions. In the immediate treatment group, OCD was diagnosed in 8 out of 17 (47%) children and 9 out of 23 (39%) of the wait-list children. Similar to Sze and Wood (2007), the Building Confidence CBT program (Wood et al., 2006) was offered to the participants and their families in 90-minute sessions over 16 weeks. Enhancements to the manual included modules which allowed for the flexibility to address poor social skills, adaptive skills deficits, circumscribed interests and stereotypies, poor attention and motivation, common co-morbidities in PDD and school-based problems when these were present (Wood et al., 2009). Three children in the immediate treatment group and one in the control condition dropped out of the study. According to the Clinical Global Impression (CGI) – Improvement Scale (National Institute of Mental Health), a seven-point scale ranging from very much improved to very much worse, all but one treatment completer in the immediate treatment group met criteria for a positive response to treatment compared to only 2 of 22 children in the wait-list condition. The ADIS (Silverman & Albano, 1996) was re-administered at post-test to determine how many of the participants continued to meet criteria for an anxiety disorder. Nine out of 14 of the treatment completers no longer met criteria for any anxiety disorder compared to only two out of 22 of the wait-list children. At 3-month follow-up, 10 children in the treatment group were re-assessed and eight remained in remission. Individual participant results were not provided so it is not possible to separately assess the effectiveness of the CBT for specifically treating OCD in the eight children with HFA. Nevertheless, this study offers preliminary support for the efficacy of an enhanced CBT program for children with HFA and co-morbid anxiety problems including OCD (Wood et al., 2009).

#### *Commonalities of Presented Studies*

The four preliminary studies that used CBT to treat OCD in children with HFA share common components. Two of the case studies (Reaven & Hepburn, 2003; Lehmkuhl et al., 2008) modified the March and Mulle (1998) manual for use with this dually diagnosed population. Sze and Wood (2007) and Wood et al. (2009) used a comparable CBT program and also emphasized the importance of adapting and individualizing the program for their population. Each of these studies stressed the importance of active parent involvement as well as making appropriate modifications such as incorporating visuals and the child's special interests into treatment to match the child's cognitive, developmental levels and learning style. Collectively, these studies each show positive preliminary results supporting the use of a CBT package, with appropriate adaptations, to treat anxiety and OCD in this population.

#### *Purpose of Current Study*

The purpose of this investigation was to replicate and extend the small number of case studies and RCT, with eight participants who had OCD, that have been successful in treating OCD in school-age children with a dual diagnosis of HFA and OCD. In particular, two case studies (Reaven & Hepburn, 2003; Lehmkuhl et al., 2008) share several common components and represent the work that is most closely in line with the current study. These commonalities include the use of the March and Mulle (1998) manual as a framework, incorporating visual strategies into the treatment program, use of self-monitoring tracking logs and increased parent participation. In addition, Lehmkuhl et al. also added a behavioural reward system to increase participant motivation. We replicated these case studies by continuing to use the March and Mulle manual to treat two children with HFA. The manual was used as a framework in planning treatment sessions, with appropriate modifications made to suit our dually diagnosed population.

We extended the existing research by adding several features to complement the collection of pre- and post-data. First, this study used a single-case experimental design, which allowed us to systematically evaluate the responses of the independent variable for each targeted behaviour. Second, we introduced the use of subjective parent data collection methods by having parents collect data on the frequency and/or duration of the behaviours as they occurred in the home between sessions. Also, objective data collection methods were also used, such as having the parent audio-record the child using the treatment strategies (e.g., self-management) in the home. Third, similar to previous RCTs (e.g. Wood et al., 2009), procedural reliability checks were used to ensure that treatment protocol was carried out properly according to the March and Mulle (1998) framework. Fourth, the inclusion of an indirect functional behavioural assessment (Cipani & Schock, 2007) made it possible to hypothesize the function(s) that the behaviours served for the children, and to address these functions (e.g., seeking parental attention) with supplemental behavioural treatments (e.g., reinforce coping behaviours and ignore compulsions). Finally, secondary outcome measures, including quality of life and consumer satisfaction assessments were used to explore the clinical significance of the research.

This study attempted to answer the following two research questions: (a) Will the use of a CBT treatment with parent involvement, in conjunction with functional behavioural assessment be successful in alleviating the participant's OCD behaviours?; (b) does lessening the child's OCD behaviours increase the family's quality of life, resulting in clinical significance?

## Method

### *Participants*

*Jake*

Jake (pseudonym), an energetic 10-year, 8-month old boy presented as bright and articulate. Jake's mother had a diagnosed anxiety disorder and she reported noticing anxiety in her son when he was a toddler. She described him as a very anxious child who was often hesitant to try new activities. He reportedly did not have many friendships, and appeared to relate better to adults than to children. Jake's mother attended all sessions, and his stepfather was present during the assessments and the introductory treatment sessions. Jake usually arrived upbeat and was seemingly ready to work. However, in the beginning, he often appeared embarrassed and refused to answer questions related to his obsessions and compulsions. This may have also been related to his limited insight into the thoughts related to his behaviours, as well as a lack of rapport with the therapist(s). As treatment progressed, and he became more familiar with the therapists and the subject matter, he appeared more comfortable in describing his thoughts and feelings.

*Diagnostic formulation.* According to the DSM-IV-TR (APA, 2000), Jake received an independent diagnosis of High Functioning Autism at the age of 3 years by his medical doctor. At 8 years of age, a psychologist suggested the diagnosis of Asperger's Syndrome (APA, 2000). According to the Autism Diagnostic Interview - Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) and criteria discussed by Lord et al. concerning a reported language delay before the age of 3, he met criteria for HFA. The ADI-R was administered by a research-reliable trained professional with a Master's degree who was not involved in the study. Jake's IQ was assessed with the Wechsler Intelligence Scale for Children IV (WISC IV; Wechsler, 2003) and his Full Scale IQ was in the Low-Average range. According to the Vineland Adaptive Behavioral Scales II (VABS II; Sparrow, Cicchetti & Balla, 2005), Jake presented as adequate in the communication and daily living skills domains and moderate-low in socialization.

Using the ADIS – Parent version (Silverman & Albano, 1996), a standardized anxiety interview, Jake met criteria for OCD. The CY-BOCS (Goodman et al., 1986) confirmed this result as Jake scored in the severe OCD range (score = 31) indicating that OCD caused serious functional impairment and treatment was warranted.

*History of OCD.* Jake's mother believed that some of her son's obsessions and compulsions stemmed from a significant childhood behavioural issue. As a young child and up until approximately 2 years ago, Jake reportedly touched his feces and smeared it over his body. His mother explained to him on several occasions that engaging in this behaviour could make him sick and she believed that when he started to understand this, his fears of contamination began. When the behaviour of touching his feces ceased, he began to avoid wiping himself altogether. It is also possible that this behaviour was related to him digging his fingernails into soap (with a previous history of handwashing) and requesting that his mom smell his fingers before a meal to ensure that he was clean and safe, especially after going to the washroom.

Jake's obsessions and compulsions fell into two main categories: (a) contamination fears and (b) fears related to death. Three behaviours that were targeted specifically and included in the research design were digging his fingernails into bars of soap, requesting his mother to smell his fingers to "check" that they were clean, and requesting that his mother recite a bedtime ritual. March and Mulle (1998) recommend starting treatment with a behaviour that the child already has some control over. For this reason, both of Jake's finger-related compulsions were targeted for intervention. The bedtime ritual, on the other hand, was targeted because it was the behaviour that was reported to cause the most distress to Jake and his family. Specifically, Jake would refuse to sleep outside his home, and would remain awake at night if he did not receive this reassurance.

*Fingernails in soap and checking his fingers.* It was reported that Jake engaged in digging his fingernails into soap and requesting that his mother smell his fingers for approximately 2 to 3 years. Regarding soap digging, it was often so severe that, as a result of digging, he broke bars of soap in half. He reported that he engaged in this behaviour to ensure that he cleaned out the bacteria from underneath his nails.

*Bedtime ritual.* It was noted that Jake's death-related fears began approximately 6 years ago. He often experienced night terrors as a child, and his mother reported that she initiated the bedtime ritual as a means of helping him to sleep. The bedtime ritual consisted of his mother saying "no bad dreams allowed - only good thoughts..." and proceeding to list off several people, places and things that were "good" or "happy" things that he could think about to help him sleep. This ritual also included a number of statements such as "you will not die from dehydration." This routine had grown into a lengthy ritualized routine that Jake requested hearing from his mother every evening before bed. He would often request to add other "good" things to the ritual or seek reassurance regarding his safety by asking questions following the ritual. Jake's mother reported that it often took at least 20 minutes to get Jake to bed. In addition to the specific bedtime ritual that was on average 30 seconds in length, Jake's mother provided him with reassurance about a number of issues during this time.

*Additional fears.* In addition to the above behaviours that were specifically targeted and included in the research design, Jake was fearful of other stimuli related to contamination and death. For instance, he reported being concerned about bacteria getting into his food. He refused to eat anything in his lunch at school that was not pre-packaged. He believed that if it was not pre-packaged, then it was contaminated. Also, Jake discussed slamming his locker door at school

to keep the bacteria out of his lunch. Further, it was reported that Jake avoided touching certain stimuli, such as elevator buttons and the foot lever on the garbage can.

Jake's other compulsions associated with worrying about death involved watching the weather every evening and reporting any concerns to his mom and stepfather. Jake would often seek reassurance from his mother that he and his family were not going to die from wind, flooding, or tornadoes, among other things. Furthermore, he was scared of what he called "poison." This consisted of any cleaning liquids that his mother used. Jake would seek reassurance from his mother that she "got all the poison down the sink" before using the bathroom if he could smell the cleaner. These behaviours were addressed throughout treatment by implementing treatment components as necessary and by providing strategies to Jake and his mother to help them deal with them in their home.

#### *Mary*

Mary (pseudonym) presented as a shy 8-year, 1-month old girl with a pleasant demeanour. Mary had a good sense of humour and commonly displayed a positive affect when coming to session. Mary's eye contact was sporadic, and although she would occasionally make eye contact, she seemed to have difficulty maintaining it. Also, she had a limited attention span, and when asked questions about OCD she often indicated that she did not want to participate and would engage in a variety of non-compliant behaviours, such as crawling onto her mother's lap or going under the table. Mary attended all sessions with her mother. Similar to Jake, Mary's mother also had a diagnosed anxiety disorder.

*Diagnostic formulation.* Mary was diagnosed with Autistic Disorder at the age of 5 years by a licensed professional. A diagnosis of Autistic Disorder was confirmed with the ADIR (Lord et al., 1994). She was identified as meeting the criteria for HFA set forth by Thede and Coolidge

(2007) as she was verbally fluent with an average IQ. Mary's IQ was assessed with the WISC-IV (Weshsler, 2003) and her Full Scale IQ was determined to be in the Low-Average range of intelligence. According to the VABS II (Sparrow et al., 2005), Mary presented as adequate in the communication domain and low in socialization and daily living skills.

According to the ADIS - Parent version, Mary met criteria for OCD (Silverman & Albano, 1996). Likewise, on the CY-BOCS (Goodman et al., 1986), Mary scored in the severe OCD range (score = 30) indicating the presence of OCD which caused serious functional impairment requiring significant help from others (March and Mulle, 1998).

Similar to Jake, Mary's obsessions and compulsions fell into two categories: (a) contamination fears; and (b) fears related to death or something bad happening. However, while Jake was likely to seek reassurance from his mother as a compulsion, Mary compulsively avoided the anxiety-provoking situations altogether. Three behaviours that were specifically targeted and used in the research design were her compulsive avoidance of wiping herself, contact with stimuli containing poison symbols, and the garbage can at school by bringing home her garbage from lunch and snacks. Mary's avoidance of wiping was targeted first as Mary experienced numerous re-occurring infections. Her avoidance of stimuli with poison symbols and the garbage at school were subsequently targeted due to the level of interference into the lives of both the participant and her family members. On the rare occasions that Mary contacted an item that she thought was contaminated, she would request that her mother wash the stimuli or that she be able to use hand sanitizer following contact.

*Compulsive avoidance of wiping.* Mary's mother reported that she had never wiped herself independently, as she was fearful of contacting germs. She would call her mother into the bathroom whenever she needed to be wiped. In the past, when Mary's parents had refused, she



would scream until someone came to clean her, and in their presence would verbally express that she was scared. On rare occasions when they were not available, she reportedly would not wipe at all. In addition, this fear of wiping also caused Mary to avoid going to the washroom altogether. Mary reported obsessing about the germs and would refuse to urinate or defecate while at school. She would wait until she got home where her mother was available to wipe her. As a result of inappropriate wiping and refusing to urinate or defecate for prolonged periods of time, she experienced several bladder and urinary infections.

*Compulsive avoidance of poison symbols.* Mary avoided any material or substance with a poison symbol on it. This behaviour had emerged over a year ago, when a presentation about safety around poisonous materials was given at her school. Mary reported that she obsessed that something bad would happen if she contacted anything with a poison symbol. She avoided several stimuli with poison symbols, including her garage, hairspray, cleaning substances and glue. This avoidance kept Mary away from engaging in activities she had previously enjoyed. For instance, she stopped going into her garage because it contained items that had poison symbols on them. Also, she had to be taken out of swimming lessons last summer because she saw buckets of chlorine near the public pool and refused to go back into the water.

*Compulsive avoidance of garbage can.* At times, during the past two school years, it was reported that Mary actively avoided the garbage can at school by bringing all her garbage from her lunch and snacks home. In session, she reported that she was not scared of the school garbage can and was not able to explain why she did not want to use it. However, when bringing her garbage to session, she remarked that it was gross or dirty. At one point, Mary revealed to her mother that another student had told her that a dead salamander was in the garbage and that was why she avoided it. In addition, Mary's mother reported that her daughter appeared to also

avoid the garbage at home as she would leave items such as Kleenex lying around rather than throwing it in the garbage and she appeared anxious when she was asked to use the garbage.

*Additional fears.* Mary feared a number of additional stimuli that were treated but not included in the research design. Similar to her fears about poison symbols, while in treatment, a presentation on safety around electricity was given at Mary's school and she became frightened of anything electrical. This new fear prevented Mary from being involved in activities she had previously enjoyed. For instance, she reportedly refused to play in a long-time friend's yard because of utility poles on her property. As well, her desk had to be moved in her classroom because she claimed it was too close to an electrical outlet.

In addition to avoiding contaminants, Mary also actively avoided stimuli that she associated with death. For instance, following a family member's funeral, Mary would no longer wear the shoes that she had worn in the cemetery. She also refused to sit in a specific seat in her van because her sister sat there after touching the deceased person.

### *Setting*

Treatment sessions took place in a family interview room in the Jack and Nora Walker Canadian Centre for Lifespan Development Research Centre at Brock University. The Research Centre mirrors an out-patient clinic setting, with a waiting room and various meeting and observation rooms. The family meeting room was a private room with a large table and several chairs. Selected assessments (e.g., cognitive assessments) were conducted in a smaller observation room in the Centre. This room was used in addition to the family meeting room when the participant and his or her parent were being assessed separately. This room was smaller and set up with a desk and two chairs. Sessions were conducted by a Master's student in Applied Disability Studies or in a co-therapy fashion by the student and an Associate Professor

with a Ph.D. in Clinical Psychology. The professor was present for five of Jake's 15 treatment sessions and three of Mary's 11 sessions as well as booster sessions for both families. The professor conducted pre-test assessments, and was present for periodic sessions to help troubleshoot any difficulties the family was experiencing as well as taking part in the child's graduation celebration.

This study received clearance from the Brock University Research Ethics Board. During the initial meeting with families, the process of informed consent/assent took place. The study was described thoroughly to parents and also to the participants using appropriate non-technical terms. The parents signed consent forms and children signed assent forms and were provided with copies to take home for future reference. These forms can be found in Appendix A.

### *Materials*

*Background history questionnaire.* The background history questionnaire collects information pertaining to the family history, school history, relationships with others including siblings, peers and stress.

### *Confirmation of PDD characteristics*

*Autism Diagnostic Interview – Revised (ADI-R).* The ADI-R (Lord et al., 1994) is a parent-report diagnostic interview that is appropriate for any individual over the age of 18 months who is suspected of having a PDD. It was used in this study to confirm diagnoses made by licensed professionals. The parent interview is comprised of 93 items and focuses on language and communication, reciprocal social interactions, and restrictive, repetitive, and stereotyped behaviours and interests. The ADI-R has good interrater reliability despite the fact that detailed and subtle psychopathological judgements are required. Also, test-retest reliability was high with all coefficients falling between .93 and .97. Interrater reliability was assessed by

Chakrabarti and Fombonne (2001), and the intraclass correlation coefficient was .86 for the total ADI-R score. The ADI-R has been found to be effective in the diagnosis of autism as well as differentiating autism from other developmental disorders. For the purpose of this study, it was used in conjunction with general observations of characteristics to confirm characteristics of PDD.

### *Cognitive assessments*

*Wechsler Intelligence Scale for Children – Fourth Edition (WISC-IV)*. The WISC-IV (Wechsler, 2003) is a clinical instrument used to assess the cognitive ability of children aged 6 years to 16 years and 11 months. The WISC-IV was used in this investigation to confirm that the participant had an IQ above 70 and therefore, met criteria for HFA (Thede & Coolidge, 2007). In typical administration, ten subsets are tested in the following four domains: verbal comprehension, perceptual reasoning, working memory and processing speed. In testing the validity of the WISC in other populations, 19 children and youth with autism (ages 7-16) and 27 youth with AS (ages 9-15) were administered the WISC. The WISC-IV has been proven to have acceptable psychometric properties.

*Vineland Adaptive Behavior Scales-II (VABS)*. The VABS (Sparrow et al., 2005) is a standardized test that can be given to the primary caregiver to complete (Parent/Caregiver Rating Form). This is an indirect test that measures quantitative and qualitative impairments in adaptive behaviour for individuals from birth and 90 years. Four domains are assessed with this scale including communication (expression and receptive), daily living skills, socialization, and motor skills (only for children under 6 or when motor function disability is suspected). Each item is rated on a scale ranging from 0 (*no never*) to 2 (*yes usually*). The internal consistency estimates are moderate to high with approximately 75% having a value of 0.75 or greater. In

general, the reliability of the assessment tends to be higher for children than for teenagers. For ages 6 to 11, the average subdomain reliabilities are in the low .80s. The test re-test reliability for ages 7 to 13 ranged between .75 and .91. Interrater reliabilities for a sample aged 7 to 18, were reported as .81 for the adaptive behaviour composite and in the mid to low .70s for the domains and subdomains.

### *OCD assessments*

*Anxiety Disorders Interview Schedule - Parent (ADIS).* The ADIS (Silverman & Albano, 1996) is a semi-structured diagnostic informant interview that is designed to be conducted with a parent. It is based on the DSM-IV criteria for all anxiety disorders. The ADIS has demonstrated acceptable psychometric properties. Specifically, Lyneham, Abbott and Rapee (2007) reported that when administered to children and adolescents, the interview provided consistent diagnostic results across different clinicians. Similarly, Silverman, Saavedra and Pina (2001) reported that both the parent and child versions of the interview were reliable over time. The OCD module of the ADIS-P was administered pre- and post-treatment, in order to confirm the presence or absence of OCD behaviours.

*Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS; See Appendix B).* The CY-BOCS (Goodman et al., 1986) is a semi-structured interview designed to determine the time spent, distress, interference, resistance and control of obsessive and compulsive symptoms for children ages 6 through 17 years. The CY-BOCS is typically completed by the child and his or her parent together but may be completed with each of them separately. The questionnaire consists of 19 questions, 10 of which are included in the scoring algorithm. Each question is rated on a 5-point ordinal scale from 0 (*none*) to 4 (*extreme*). A score of 10 to 17 indicates mild OCD, where distress may be present but not dysfunction. Scores from 18 to 29

indicate moderate OCD which causes both distress and functional impairment, and scores above 30 indicate severe OCD that causes significant impairment in daily functioning. The goal in treatment is to reach a score indicating a subclinical level of OCD, which is generally considered to be in the range of 8 to 10 (March and Mulle, 1998). In a study by Storch et al. (2004), the psychometric properties of the CY-BOCS were reported as acceptable. Internal consistency was acceptable for the obsession and compulsion severity scores (.80 and .82) and total score (.90). Test re-test reliability was assessed 40 days after the first test and scores remained acceptable.

### *Functional assessment*

*Questions about Behaviour Function (QABF) - Revised.* See Appendix C for a copy of the revised QABF. The QABF (Matson & Vollmer, 1995) is a behavioural checklist designed to identify the functions of behaviour. The measure appears to have good preliminary psychometric properties with individuals with developmental disabilities (Matson, Bamburg, Cherry & Paclawskyj, 1999). Furthermore, Singh, et al. (2006) adapted the QABF for use with individuals with serious and persistent mental illnesses including, schizophrenia and anxiety. They found inter-rater agreement coefficients for the five factors (range .96-.98) and high test-retest reliability (range .84-.92) indicating substantial internal consistency for each of the functions examined. It was concluded that the QABF was a psychometrically valid screening instrument for developing initial hypotheses of the functions of maladaptive behaviour in individuals with mental health issues (Singh, et al.). The original QABF includes five items to examine four acknowledged functions of behaviour including: (a) attention from others, (b) self-stimulation, (c) access to tangible, and (d) escape. Each of these items is rated on a four point scale from 0 (*never*) to 3 (*often*). Although all functions were addressed, those with the highest total ratings and/or the highest number of items endorsed were considered primary. In the

definition of OCD (APA, 2000), compulsions are typically engaged in to relieve obsessional thoughts. To examine anxiety reduction as a possible maintaining function of OCD (APA), the QABF was revised and five additional questions were added. Questions were based on the DSM-IV and included the following: (a) Does the person seem to engage in the behaviour to get rid of uncomfortable thoughts/images/impulses?; (b) engage in the behaviour to reduce stress or prevent some dreaded situation from occurring (but the behaviour is not connected in a realistic way with that they are designed to neutralize?; (c) engages in the behaviour in response to a thought or according to a rule that must be applied rigidly?; (d) engages in the behaviour to cope with thoughts/images/impulses?, and (e) does the child appear worried (i.e. facial expressions, body tightened) before engaging in the behaviour?

#### *Secondary outcome measures*

*Quality of life questionnaire.* See Appendix D for the quality of life measure. The Family Quality of Life Questionnaire (Feldman, Condillac, Tough, Hunt & Griffiths, 2002) is a self-report measure designed to determine how much the child's OCD behaviours affect their daily functioning and overall quality of life. The parent is asked to rate items on a 7-point likert scale from 1 (*minimally*) to 7 (*extremely*) according to how much the child's OCD behaviours interfere with various domains of child and family life (e.g., learning, community involvement, ability to make friends, attend social functions, etc.). The instrument consists of eight questions which includes statements such as: "Does your child's behaviour interfere with the child's opportunities to develop friendships?" Parents completed the questionnaire prior to, and upon completion of treatment.

*Consumer satisfaction questionnaire.* See Appendix E for Consumer Satisfaction Questionnaire. The Consumer Satisfaction Scale (Feldman et al., 2002) is a self-report measure

designed to evaluate the consumer's perceived satisfaction, level of involvement, and effectiveness of the current treatment on a 7-point likert scale from 1 (*not satisfied*) to 7 (*very satisfied*). Parents only completed the questionnaire at post-treatment as both mothers reported that they had not previously utilized services for their child's anxiety.

*March and Mulle manual.* The March and Mulle (1998) treatment manual provides guidelines and goals for each session and works through three phases of treatment: (a) awareness training; (b) cognitive training; and (c) graded exposure and response prevention. The manual suggests simultaneously treating all OCD behaviours within each phase.

*Awareness Training (AT).* In the awareness phase, OCD is linked to a specific set of behaviours and discussed as external to the child and not his or her fault. This conversation allows the participants to externalize OCD and gain a general awareness of the topic. In attempting to make OCD a discrete enemy and not just a bad habit, the participants are given the opportunity to give OCD a nasty nickname (March & Mulle, 1998). In AT, the ideas of being the boss and bossing back OCD are discussed. In addition, the participant lists and draws their support team, often consisting of his or her parents and family as well as the therapists. The process of mapping the child's OCD behaviours is started during the AT sessions and continues into the cognitive training phase.

*Cognitive Training (CT).* In the cognitive training phase, the goal is to teach the child cognitive tactics for resisting OCD. The child is provided with a cognitive "tool kit" that he/she can use during the next phase of treatment, exposure and response prevention (ERP) (March & Mulle, 1998). There are many goals within this treatment phase including increasing the child's sense of personal efficacy, using psychoeducation to reinforce accurate information about OCD and practicing cognitive resistance ("bossing back OCD"). The three main



techniques used in CT include: (a) constructive self-talk, (b) cognitive restructuring, and (c) cultivating nonattachment. The general approach to increasing constructive self-talk is to replace maladaptive thoughts with realistic positive self-statements that focus on the child's ability to fight OCD using the tools learned in treatment. The child is also taught to boss back OCD with coping statements such as, "Can't catch me this time, OCD." In cognitive restructuring, the child's faulty assumptions about the power of OCD are directly challenged in conversations with the therapist. In cultivating nonattachment, the child is taught how to disengage his or her attention away from the emotionally aversive cognitive intrusions that characterize OCD. As stated previously, the process of mapping OCD is also continued in CT. This process aims to "map the child's experience with OCD, including specific obsessions, compulsions, triggers, avoidance behaviours, and consequences" (March & Mulle, p. 43). The child uses the fear thermometer to rate the anxiety related to each of the behaviours. The fear thermometer is a child-friendly tool, similar to the parent-rating form, that is used to rate anxiety levels on a scale of 0 (*not at all*) to 8 (*very very much*). This information is then used to create a stimulus hierarchy which illustrates where each child has some success in bossing back OCD and where he/she feels helpless.

*Graded Exposure and Response Prevention (ERP).* The third stage is graded exposure and response prevention. This includes therapist-assisted imaginal exposure (when appropriate) as well as in vivo exposures. In the exposure phase, the child exposes him or herself to the object, action or thought that produces anxiety by coming into contact with the feared stimulus. In response prevention, the rituals or avoidance behaviours that the child normally engaged in are blocked. ERP for avoidance behaviours may involve both contrived and natural exposures where the child engages with the feared stimulus for gradually increasing periods of

time. The child is involved in choosing the targets he or she wants to work on and the stimulus hierarchy is updated regularly to show the child that he or she is becoming more competent at resisting obsessions and compulsions (March & Mulle, 1998).

### *Procedure*

*Pre-test assessments.* For both participants, the first three meetings focused on establishing rapport and completing pre-treatment assessments including the background history questionnaire, all OCD and PDD assessments, cognitive assessments and secondary outcome measures.

*Data collection.* Using information gathered from the ADIS, operational definitions of OCD behaviours were determined with the parent. See Appendix F for operational definitions. Data collection forms were created and explained to each parent, and they were instructed on data collection expectations. Based on the results of the ADIS, the forms were designed to target the behaviours that were identified. The questions on the data collection form addressed all behaviours reported by participants' parents. Parents rated their child's individual behaviours on a scale from 1 (*not at all*) to 10 (*very, very much*). In baseline, parents were asked to collect data at least three days each week. Once treatment commenced, the two mothers began collecting data on a daily basis in the home setting between each session. See Appendix G for data collection forms.

For Jake, two questions were included that assessed his behaviour of digging his fingernails into the soap. One question assessed his request for his mother to smell his fingers. For Jake's bedtime ritual, data was collected in two ways. First, the subjective parent rating of "how much" she had to say the bedtime ritual was used. Also, objective data collection was

possible via audio-recorder to capture the duration of his bedtime ritual. See Table 1 for the parent-report questions for each of Jake's targeted behaviours.

Table 1

*Parent-Report Questions for Jake*

<b>Compulsion</b>	<b>Question</b>
1. Digging fingernails into soap	Did Jake stick his fingernails into the soap today? (yes/no)
1. Digging fingernails into soap	How much did Jake stick his fingernails into the soap?
2. Requesting mother to "check" his fingers	Overall, how much did Jake ask you to smell his fingers today?
3. Requesting mother to recite bedtime ritual	Overall, how much did Jake seek reassurance by having you say or asking you to repeat the bedtime ritual?

Similarly, for Mary, the data collection form included the three behaviours used in the research design as well as others that were indirectly targeted to keep track of all behaviour changes. Mary's mother rated avoidance of wiping separately for both wiping urine and feces. Table 2 shows the questions used to assess each of Mary's targeted behaviours.

Table 2

*Parent Report Questions for Mary*

<b>Compulsion</b>	<b>Question</b>
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1. Avoiding wiping herself	Overall, how much did Mary avoid wiping herself after using the bathroom – For urine? For feces?
2. Avoiding items with poison symbols	Overall, how much did Mary avoid something because of a poison symbol?
3. Avoiding garbage can at school	Overall, how much of her lunch and snacks did Mary bring home to avoid the garbage at school?

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*Comprehensive behavioural assessment.* The completion of an ongoing functional behaviour assessment, comprised of parent interviews, therapist observations and child self-reports (Feldman, Condillac, Tough, Hunt & Griffiths, 2002) was used to obtain information regarding possible maintaining variables of the behaviours. We also gathered information regarding additional triggers of behaviours (i.e., setting events, antecedents). Although, both children could not identify any triggers, their mothers indicated that when fatigued or stressed, the behaviours appeared to escalate. In the presence of these variables, we encouraged both parents to persist with treatment and, in some cases, to lower demands. The information from the comprehensive behavioural assessment was used throughout all components of treatment.

*Revised QABF results.* QABFs (with the addition of five questions related to escape from obsessions; see Appendix C) were completed with Jake's mother for six of his compulsions. The QABF was rated on the following scale: 0 (*never*), 1 (*rarely*), 2 (*sometimes*), and 3 (*often*). Results indicated that the primary function of each of his compulsions was anxiety reduction. Second, physical ailments were endorsed as a possible function of Jake's requesting

his mother to smell his fingers and perform the bedtime ritual, but to a lesser extent than escape from thoughts. For finger-smelling, all five items regarding escape from obsessions and physical discomfort were endorsed with an average rating of 2.8 and 2.4, respectively. Regarding reassurance seeking through the bedtime ritual, all five anxiety reduction items were endorsed with an average rating of 2.8. Only four of five items were endorsed for physical discomfort with an average rating of 2. Although not endorsed by his mother as a perceived function, since many of Jake's compulsions involved seeking reassurance, it is possible that reassurance served as social attention (positive reinforcement). In session, Jake often engaged in behaviours that were likely maintained by attention. For example, Jake was often "performing" and acted very dramatically; he also sought praise for his compliant behaviours or success with treatment by asking the therapists or his mother whether he was doing a good job.

In Mary's case, her mother completed three QABFs, one for each of Mary's targeted behaviours, and escape from obsessive thoughts was the primary function endorsed. For avoidance of wiping, all five items related to anxiety reduction were rated as a 3, indicating that they often occurred. Similarly, for avoidance of poison symbols and the garbage can, four of five items related to escape from obsessions were endorsed as the primary function with an average rating of 3. Similar to Jake, in session Mary often engaged in behaviours that were likely maintained by attention such as non-compliant behaviours, including crawling under the table or acting in a childish manner (e.g., whining and crawling onto her mother's lap). Although not endorsed on the QABF, based on anecdotal report it appeared that Mary's avoidance of the garbage can at school may be maintained, at least in part, by escape from demands. Based on her mother's report that Mary exhibits very poor organization skills, she may have learned that

bringing home all her garbage along with other school items, such as notebooks was less effort than deciphering which items belonged in the garbage and throwing them in the garbage can.

The procedure for both participants will now be described in detail with additional behavioural supplements mentioned in their chronologically appropriate position. These behavioural supplements will be explained in further detail under the modifications section that follows.

*Jake.* Jake's three targeted behaviours were addressed in 15 sessions over a period of 5 months. Sessions were approximately 1.5 hours in length and occurred once per week. Similar to the suggested sequence from March and Mulle (1998), all behaviours were treated in AT. Then, different from March and Mulle, the first behaviour was treated with CT and ERP while the other behaviours remained on baseline. When a treatment effect was evident for the first behaviour, CT and ERP were applied to subsequent behaviours. As well, we made a clinical decision to offer CT and ERP together because CT was shortened in order to accommodate for Jake's limited insight into obsessive thoughts.

*Awareness training.* Awareness training was conducted in three sessions. In AT, OCD was explained to Jake as something outside of him that is not his fault. He was introduced to the concept of being the boss and that his therapists/family/friends were his allies. He drew a picture to represent his support team that was going to help him fight OCD. Using the fear thermometer, Jake was able to list each of his OCD behaviours and rate their severity. After Jake rated each behaviour, he worked with the therapist to determine where the behaviour belonged on his map of OCD according to who had control of it. To facilitate this activity, three circles were drawn and labelled Jake, Jake and OCD, or OCD alone, and with the help of his mother and therapist, Jake attached each of his behaviours to the circle where he felt it belonged.

*CT and ERP for fingernails in the soap.* In treatment session 4, CT commenced for Jake's soap digging. As mentioned previously, Jake's behaviour of digging his fingernails into bars of soap was targeted as the first behaviour to receive treatment because it was in the "transition zone." In other words, Jake already had some control over this behaviour as he did not engage in the behaviour every time he washed his hands. When encouraged to give OCD a nickname, Jake decided to call it OOD, which stood for "Outrageous Obsessive Disorder." During CT, the idea of a coping "toolkit" was introduced. With the help of his mother, Jake created a number of positive coping statements for his toolkit. He started with general coping statements, such as "I'm the boss of OOD" and "I'm going to get revenge on you OOD." Following psychoeducation about the purpose of germs and that some germs are necessary to keep our immune systems in good working order, he created coping statements specific to the behaviour, such as "some germs are good for me." Using drawings and stickers, he personalized all of his coping statement cards. In session, it appeared that he was excited about these coping statements and they appeared useful in helping Jake externalize OCD as something he could beat. For instance, Jake often stated that he was going to "get revenge on OOD." However, his mother reported that he rarely rehearsed the statements outside of session and he did not use them during exposures unless prompted to do so.

Jake engaged in both imaginal and in vivo exposures for his soap digging behaviour. We had Jake practice at home and then present to us how he washed his hands after going to the bathroom using an imaginary sink and soap. Although, he appeared apprehensive at first, Jake was eventually able to bring a bar of soap into the clinic washroom and practice not sticking his fingernails in the soap. In doing this, Jake was able to practice using his coping statements and strategies in simulated and real situations to help him resist sticking his fingernails in the soap.

Following these exposures, Jake used the fear thermometer to rate that his anxiety had quickly dropped. When exposures took place in session over subsequent weeks, Jake reported that he had no anxiety. However, he reported continued challenges with this behaviour in the home. At this point, self-monitoring was introduced, which involved having Jake self-monitor his success with exposures of resisting soap digging. This was completed using a checklist in the home where after washing his hands, Jake would report whether he was successful in resisting sticking his fingernails in the soap.

*CT and ERP for requesting that his mom check his fingers.* After a treatment effect was seen for Jake's first behaviour, the general coping statements were reviewed for Jake's second targeted behaviour of requesting that his mother smell his fingers. Cognitive restructuring (psychoeducation) appeared useful with this behaviour, as it helped in showing Jake that it is not possible to determine cleanliness by smelling hands. We explained to Jake that "it is possible for your hands to smell good but not actually be clean" and further that "your mother can only guess whether your hands are clean by smelling them." We explained that washing his hands with soap was the only guaranteed means of ensuring their cleanliness. The revised QABF for this behaviour indicated that, along with anxiety reduction, physical pain may have served as a secondary function. To address this, we asked Jake's mother to ensure that she continued with the interventions even when he was ill or in pain.

In addition, to address the possibility that reassurance served as attention (positive reinforcement), the therapist asked Jake's mother to reinforce him with social praise when he redirected himself to activities or used his coping strategies appropriately. When Jake attempted to seek reassurance from her, she was asked to answer him only once and then ignore any further



requests. She was instructed to redirect him to a coping statement or to washing his hands if he was uncertain about their cleanliness.

Jake was involved in choosing ERP targets. The first target set was to stop making the request for his mother to smell his fingers before breakfast because he felt he was less likely to do it at that time of day. His goal was to engage in the behaviour in the morning no more than two times in a one week period. When he was successful on each day for one week, his goal was adjusted to include resisting seeking reassurance at all meals. Jake engaged in self-monitoring where he kept track of how many times he requested his mother to smell his fingers at each meal. This form was also used to facilitate his token economy by documenting when he had achieved his goals and was brought into session each week to show the therapists.

*CT and ERP for requesting to hear the bedtime ritual.* Jake's mother initiated ERP for the bedtime ritual in the home before the therapists had planned to. She reported that her familiarity with the treatment package as well as her motivation to decrease the ritual had prompted her to do so. Jake's mother engaged him in gradual ERP as they slowly cut out certain things and people from the ritual, gradually shortening it. As well, ERP was continued and CT was added by the therapists and involved revisiting his general coping statements and a discussion of the low probability that he would die if he was not able to hear the bedtime ritual. Jake was also able to discuss what he thought typical children said to their parents before bed, such as "good night" and "see you tomorrow." It was clear that Jake recognized this behaviour as excessive or atypical as he reported asking his mother to whisper it in his ear if other children were present when he went to bed. According to the revised QABF, this behaviour was more likely to occur when Jake experienced physical pain. Therefore, similar to finger smelling, we asked his mother to continue to address it with the same strategies, as well as lowering the

demands so that Jake received higher levels of reinforcement for alternative behaviours on days where he was ill.

Eventually, the ritual was shortened to only a sentence. Jake would say “good night, love you, see you in the morning” and his mother would repeat this back. At this point, to ensure there was flexibility within the routine, we generated a variety of phrases that Jake could say to his mother before bed, such as “have a good night” or “see you later.” He used the list to choose a different phrase to say each night and then the list was faded out when his mother observed that they were engaging in a natural and varied bedtime routine.

*Relapse prevention and booster sessions.* Relapse prevention took place following training and intermittently during follow-up sessions. This involved having Jake imagine possible OCD problems he might experience in the future and determine how he would deal with them. Initially, Jake’s mother needed to assist her son as his only suggestion was to return to the clinic. Following post-test, Jake was seen for four booster sessions to work on his avoidance of wiping, a behaviour that had been present throughout treatment but not acknowledged until this time. Each component of the treatment package was revisited and the token economy was used for this behaviour. Following these sessions, Jake still insisted that he would return to the clinic if any new behaviours arose but he also verbalized that he and his mother could successfully work as a team in the home now that they had the strategies.

*Graduation.* The graduation ceremony for Jake was held 2 months after the post-test when the majority of his residual OCD behaviours had decreased. Jake’s grandmother was present for the session and Jake was able to describe his stimulus map and other materials from the treatment package. During this session, Jake verbalized that he was proud of himself and that

the treatment had really helped him. He was also presented with a certificate for successfully bossing back OCD.

*Mary.* Over the course of 4 months, Mary's treatment was offered in eleven 1 to 1.5 hour sessions weekly or bi-weekly. Similar to Jake's procedure, Mary's behaviours were treated one at a time and CT and ERP were applied simultaneously. The procedure for Mary followed the same framework as Jake but moved at a quicker pace as the development of coping statements was the only component in CT that was used extensively. As well, Mary showed a high level of motivation. She appeared to be extremely motivated by social praise from the therapists as well as the opportunity to update her stimulus map by moving individual behaviours to the circle that indicated she now had control of it. Her enthusiasm regarding seeing the therapist and making changes to her stimulus map may also have led to response generalization. For instance, Mary began using strategies developed for her avoidance of wiping to help her with her fears of poison symbols before this second behaviour was specifically targeted.

Mary's treatment commenced when there was a decrease in Jake's first behaviour. Mary's avoidance of wiping was the first behaviour targeted because during the assessment phase and while waiting for treatment, Mary had started wiping herself on occasion so it was clear that she was motivated to change this behaviour.

*Awareness training.* Awareness training for Mary was completed in two sessions and involved the same components used with Jake. Mary experienced difficulty in using the fear thermometer. When asked, she often used the thermometer in a dichotomous manner, either rating behaviours as an 8 (*bothers her very very much*) or as a 0 (*not at all*). However, she was successful in completing her stimulus hierarchy and determining whether she had complete control, she and OCD shared control or whether OCD had complete control over the behaviours.

*Avoidance of wiping.* For Mary's first targeted behaviour, she reported that she avoided wiping because she was worried about contacting germs. Therefore, psychoeducation was provided around the topic of germs and that she was more likely to contact germs if she was not wiping properly and feces was getting onto her clothing. Mary rated wiping urine as less anxiety-provoking than wiping feces and therefore, it was addressed first. As well, a list of pros and cons for wiping and not wiping was generated to help her understand that not wiping properly or not wiping at all were unsafe options. Mary was also able to develop general coping statements and use them appropriately during treatment. Although, cognitive training including psychoeducation, narrative therapy and the creation of coping statements were attempted to help with Mary's avoidance of wiping, only the coping statements appeared useful.

In ERP, a checklist of the steps necessary to wipe properly was developed. Mary was instructed to check off each step that she completed and her mother would add a sticker to the checklist upon completion of the steps. Graded ERP began with having Mary complete only half of the wiping steps, and when successful, progressively increasing what she was required to do independently. Following 3 weeks where Mary often wiped urine completely independently, we began to require her to also use the checklist for wiping feces.

*Avoidance of poison symbols.* For Mary's second targeted behaviour, psychoeducation was provided around the meaning of poison symbol and in which situations they were dangerous. With Mary's assistance, several items, both naturally-occurring and contrived, that she would normally avoid were selected as ERP targets for each week. Mary's mother would contrive several situations in the home in attempt to expose Mary to these items. During these exposures, she would encourage her daughter to use her coping statements and get as close as she could to the items. There were seven stimuli that had naturally occurred during

baseline, which Mary's mother exposed her to within treatment, including the garage, boot spray, Lysol, goop glue, googoogone, lamp oil and hairspray. These items had been reported as anxiety provoking in the past by Mary's mother who had observed Mary refusing to contact them. Four other items, rubbing alcohol, WD40, Windex, and windshield washer fluid were contacted only in treatment in both contrived and natural situations.

*Avoidance of garbage can at school.* In CT, general coping statements were reviewed and Mary was told that she was responsible for throwing out her garbage whether it was at school or when she got home. We tried to help Mary understand that throwing her garbage out at school would require less effort than packing it up, bringing it home and throwing it out. Mary's mother reported that the Educational Assistant in Mary's classroom began prompting her to throw her items out and placed a reminder note on her desk before we had begun treatment on the behaviour. According to parent-report, this was having some effect on the behaviour but it remained inconsistent. Our treatment involved encouraging Mary to use the garbage can at school as well as placing a reminder in her lunch bag. A monitoring checklist was also used by Mary and her mother to track how many items of garbage Mary took to school and how many she brought home. Mary's mother placed a sticker on the checklist each day that no garbage was brought home and the sheet was brought into session each week for the therapist to also praise her work. Finally, we required that any garbage Mary brought home from her lunch was kept and brought into the next week's session. In session, we exposed her to various public garbage cans by requiring her to throw out all of the garbage that was brought in. After 2 weeks of bringing in items, Mary no longer brought any of her garbage home from school.

*Relapse prevention, graduation and booster sessions.* Relapse prevention was provided in one session for Mary in the same manner as it was for Jake. Similar to Jake, Mary

had difficulty trying to imagine what she would do if OCD behaviours returned in the future. At this time, all behaviours were reportedly resolved and Mary was presented with her graduation certificate. Approximately one month later, Mary's mother requested a meeting with the therapists when some of the behaviours began to reoccur. Mary's mother reported that after her daughter was placed on a bladder retraining program by her physician and was required to go to the washroom several times a day, she began to refuse to wipe feces again. At the same time, she also began avoiding the garbage can at school. Mary's mother had re-initiated treatment on these behaviours by re-instating some of the strategies learned in session and offering Mary a preferred item for being successful. We met with her and helped devise a plan, incorporating several items from the original treatment package that she could carry out in the home. This included reviewing concepts from session, creating a stimulus map to refer to in the home and the use of a strong external reinforcer to help reduce the resurgence in Mary's avoidance of wiping feces and the garbage can at school.

### *Modifications of Treatment Protocol*

Similar to previous case studies (Reaven & Hepburn, 2003; Lehmkuhl et al., 2008), a number of modifications were made to the March and Mulle (1998) manual for both participants. First, the completion of the ongoing comprehensive behavioural assessments allowed us to hypothesize possible functions of the children's compulsions. As mentioned previously, the revised indirect behavioural assessment mainly revealed that the participant's OCD behaviours were maintained by attempts to escape from obsessions. However, as indicated in the treatment protocol, when other functions were endorsed or the therapists recognized other perceived functions that may have played a factor, they were addressed accordingly.

Other modifications included the presence of preferred items in session to motivate the participants. For Jake, this included computer time, and Mary liked to colour her favourite television characters. For Jake, reinforcers were chosen based on a list of items that he comprised and ordered in terms of his preference. A token economy was put into place to reinforce Jake for meeting treatment goals each week (Cooper, Heron & Heward, 2007). Jake received a pre-determined number of points for practicing his coping statements and being successful in exposure tasks, that he could trade in for small items such as staying up 15 minutes later or save up for a large item like a videogame. Unlike with Jake, tangibles were used to a lesser extent with Mary. She preferred to attend session and participate in the process of updating her stimulus map and receiving praise from the therapist, who likely functioned as a conditioned positive reinforcer. However, tangibles were only tied to specific tasks following relapse.

Finally, each session involved active parent involvement. In session, parents of both participants were trained to act as coaches to prompt their child to verbalize his or her thoughts and feelings as well as help the therapist individualize treatment to their child. In between sessions, parents were responsible for collecting data and providing assistance for exposure tasks in the home environment.

### *Research Design*

A multiple baseline design across participants and behaviours was used (Cooper, Heron & Heward, 2007). In following this research design, the independent variable (the function-based CBT, in our case) was applied to one participant while the second participant remained on baseline. After a treatment effect for the first participant's behaviour was shown, treatment on his second behaviour and the first behaviour of the second participant began. In a multiple baseline

design across behaviours and participants, experimental control is demonstrated by each behaviour changing when, and only when, the treatment is applied to it (Cooper et. al.).

### *Procedural Reliability*

Procedural reliability is the extent to which a procedure is administered exactly as planned (Cooper et al., 2007). A treatment checklist for each component (AT, CT, ERP, relapse prevention and graduation) was created based on the primary goals of the treatment according to March and Mulle (1998) and fidelity checks were conducted by having a trained naive observer view the videotapes of sessions and complete the checklist to ensure treatment components were being carried out in session. Treatment integrity checks were completed for approximately 60% of sessions. This equated to assessing the treatment of two behaviours for Jake and one behaviour for Mary, as well as relapse prevention and graduation for both participants. The research assistant assessed the first behaviour for both children and randomly selected a second behaviour for Jake. Agreement on treatment components completed was calculated by dividing the number of agreements by the number of agreements plus disagreements and multiplying by 100 (Copper et al.). All included treatment components were completed. See Appendix H for the treatment integrity checklist.

For both children, the March and Mulle (1998) framework was followed closely, however, there were a small amount of treatment features that were not used in the treatment package. Although they were listed as goals by March and Mulle, the therapist and her supervisor decided that these components were not appropriate for these participants. An example of a treatment feature that was not used involved showing the child a picture of a typical brain and a brain of an individual with OCD and explaining the differences in neurological brain functioning. This was seen as inappropriate for the young children in this study and previous



parents have requested that it not be included. For Mary, only 4.5% of items were not used because they were not appropriate. For Jake, 2% of items were not used and 4.5% of items were not recorded on video and therefore, could not be coded but were noted as completed in the therapist's case notes.

In addition, a checklist of the steps required for wiping was created and followed by Mary and her mother in the home setting. This checklist provided the therapists with an indication of how accurately the treatment was being carried out and could therefore be considered a form of procedural reliability. Mary and her mother completed a wiping checklist for 10 weeks. The checklist included six steps necessary for wiping successfully and Mary would check off each item after she completed it. Mary's mother would attach a sticker to the checklist whenever Mary was successful in completing the steps. This checklist was completed as specified 100% of the time.

## Results

The standardized and secondary outcome measures were compared pre- to post treatment and at follow-up. The behavioural data was primarily analysed through visual inspection. This approach involves the systematic visual comparison of changes in the target behaviours within and across conditions. Visual inspection involves interpretation of the level, trend and variability throughout baseline and across the treatment phases (Horner et al., 2004). The results from the visual inspection allow us to determine where functional relationships exist between the treatment and the OC behaviours. Both subjective and objective data for the targeted behaviours were graphed. The parent-report ratings were graphed separately for each targeted behaviour.

In following the multiple baseline design both across behaviours and participants, the treatment of Jake's soap digging, was commenced first. Jake's remaining behaviours and Mary's

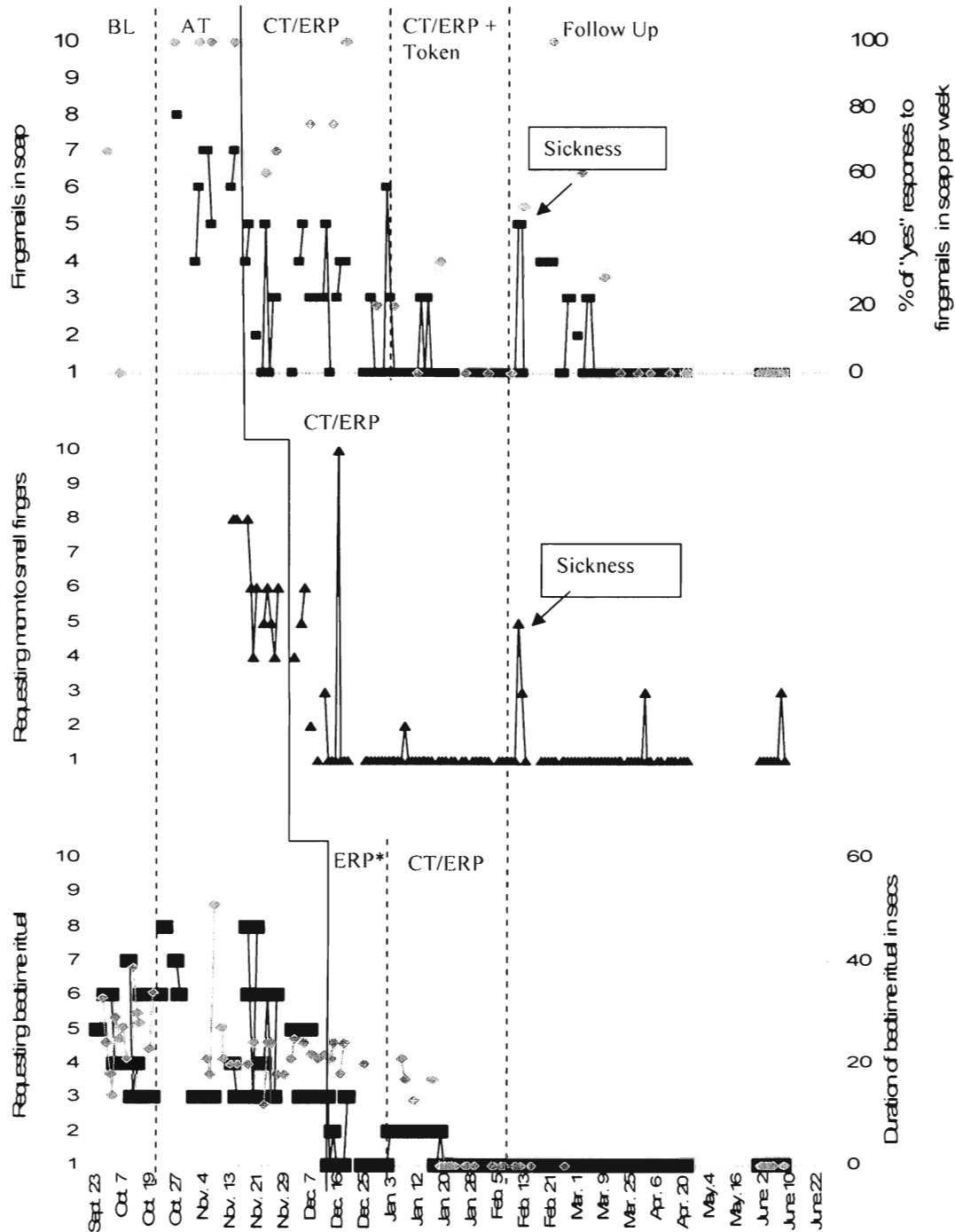
behaviours were kept on baseline. When a treatment effect was evident for soap digging, treatment commenced for Jake's second targeted behaviour, requesting for his mother to check his fingers. Treatment for Mary's first behaviour, avoidance of wiping also began at this time. Treatment continued in this manner until the three targeted behaviours for each participant were treated.

#### *Visual Inspection of Jake's Parent-Report Data*

The three graphs in Figure 1 show Jake's three targeted behaviours. Overall, for all three behaviours, AT alone did not appear to have a treatment effect. When CT and ERP were simultaneously applied, the behaviours decreased to low levels that were maintained at follow-up.

*Fingernails in the soap.* On the data collection form, Jake's mother completed two questions related to his soap digging. In the top graph of Figure 1, see parent ratings regarding the question: "How much did Jake stick his fingernails into the soap?" This was rated on a scale of 1 (*not at all*) to 10 (*very, very much*) and is graphed on the left Y axis. In AT, the parent's responses regarding the severity rating ranged from four to eight with an average of 6.25. In treatment, when CT and graded ERP were applied simultaneously, the behaviour decreased but remained variable ranging from one to six with an average rating of 2.85 for a period of 7 weeks. When the token economy was added to the existing treatment package, the behaviour immediately became steady and remained at zero-levels for 1 month. This behaviour reportedly reoccurred during the first month of follow-up, when Jake became ill. The behaviour returned to zero-levels following his illness and has remained stable for seven weeks. The tokens were faded

Figure 1. Multiple baseline results for Jake across three behaviours.



\*Parent-initiated ERP.

Graph 1 (Top): Black squares (left axis) = Rating of fingernails in the soap; Grey diamonds (right axis) = % of yes responses per week.

Graph 3 (Bottom): Black squares (left axis) = Rating of bedtime ritual; Grey diamonds (right axis) = Duration of bedtime ritual in seconds.

for these targeted behaviours and new criteria were set to address other behaviours.

In addition to the severity rating, the mean percentage of “yes” responses per week for “Did Jake stick his fingernails in the soap today?” is graphed on the right Y axis. In baseline and AT, data was collected 3 days per week for 4 weeks. In baseline, Jake dug his fingernails in the soap, 66.6% over 4 weeks; During AT, the percentage per week that nail marks were evident in the soap rose to 100% over 4 weeks. When CT and ERP began, data collection increased to approximately 5 days per week and the behaviour remained variable, ranging from occurring 60 to 100% per week over 5 weeks. This data mirrors the parent-reported severity data, in that after 6 weeks, the behaviour dropped to zero levels and remained stable for 3 months.

*Requesting that mother smell fingers.* When a treatment effect occurred for soap digging, treatment for Jake’s requests of his mother to smell his fingers commenced. See the second graph of Figure 1 for data on this behaviour. It was assessed by Jake’s mother’s rating of the following question: “How much did Jake ask you to smell his fingers today?” This was rated on a scale of 1 (*not at all*) to 10 (*very, very often*). During AT, this behaviour was variable, ranging from four to eight with an average rating of six. When CT and ERP were applied to this behaviour, it decreased to zero-levels within 2 weeks. During follow-up, there was one spike in this behaviour associated with a sickness, which occurred simultaneously with soap digging.

*Bedtime ritual.* See graph 3 in Figure 1 for parent-ratings of Jake’s bedtime routine. The subjective parent rating of “how much did Jake seek reassurance by having you say or asking you to repeat the bedtime ritual?” is graphed on the left Y axis. This was rated on a scale of 1 (*not at all*) to 10 (*very, very much*). In baseline, the behaviour rating ranged from three to seven, with an average rating of 4.75. In AT, similar to baseline, the behaviour remained variable, ranging from three to eight, with an average rating of 4.45. When ERP was initiated by Jake’s

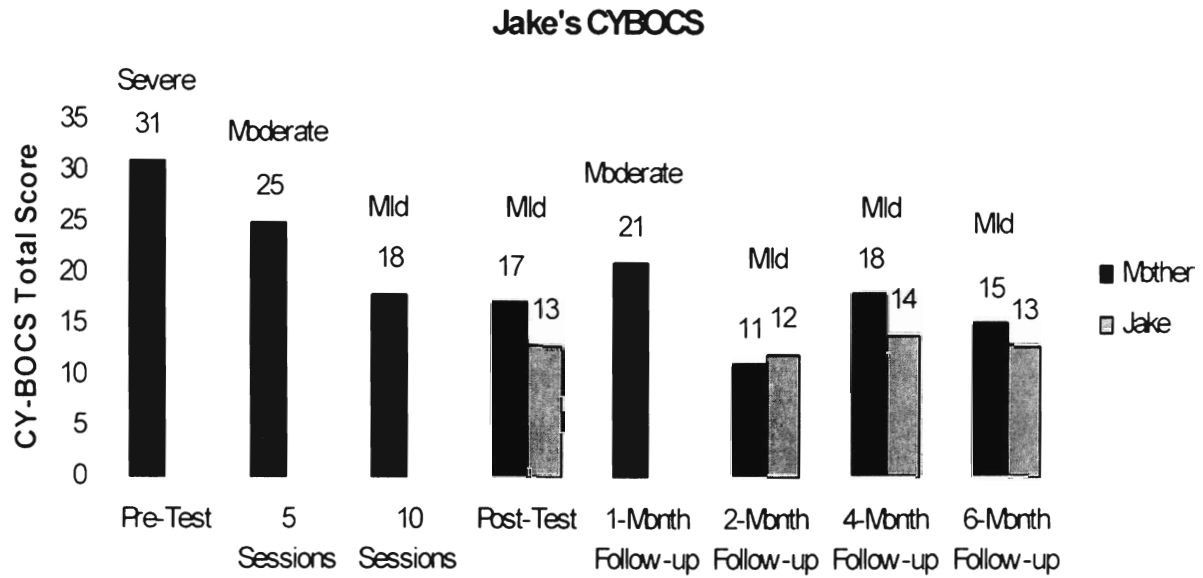
parents, the parent rating decreased to a lower steady level, ranging from one to three with an average rating of 1.33. When CT was added by the therapists and ERP was continued, the ratings decreased to zero-levels within 3 weeks and the ritual remained non-existent for 6 months.

Showing a similar trend, the duration of the bedtime routine also decreased steadily to zero-levels following CT and ERP. This objective data was collected via audiorecorder and a trained research assistant determined the length of the ritual in seconds. The duration of the bedtime ritual is graphed on the right Y axis. In baseline, the average length of the bedtime ritual was 26.5 seconds. With parent-initiated ERP, the average duration decreased slightly to 21.4 seconds. When CT and ERP (therapist-initiated) were added to the existing treatment package, the behaviour decreased and after 9 days, the ritual had stopped occurring. Similar to the parent-reported data, for 6 months, the ritual remained non-existent.

#### *Results of ADIS, CY-BOCS and Secondary Outcome Measures*

See Figure 2 for Jake's pre-test, in treatment, post-treatment, and follow-up results. At post-test, the ADIS (Silverman & Albano, 1996) indicated that Jake's OCD behaviours had decreased as less behaviours were endorsed and the rated level of distress decreased, however he still met criteria for OCD. Similar to the ADIS, Jake's CY-BOCS score, as reported by his mother, decreased 45% from pre-test to post-test. At post-test, Jake's CY-BOCS score was 17, indicating a decrease from severe to mild OCD. This means that the distress associated with OCD was lessened and another individual was no longer needed to help the child get through the day (March & Mulle, 1998). At 1-month follow-up, Jake's CY-BOCS score increased to 21 as new behaviours, such as avoidance of wiping, were addressed in booster sessions. At a 2-month follow-up, when these other contamination issues were resolved, Jake's CY-BOCS score was 11,

Figure 2. Jake's CY-BOCS scores across treatment and QOL scores at pre-test, in treatment, post-treatment and follow-up.



a 64.5% drop from pre-test. At 4-month follow-up, the CY-BOCS rating remained in the mild range.

At the onset of treatment, Jake had difficulty recognizing his obsessions and compulsions and therefore would not have been aware enough to complete the CY-BOCS on his own. However, at post-test, Jake had shown improvement in his awareness and recognition of his obsessions and it appeared that he could adequately rate his OCD symptoms. The CY-BOCS was completed with him at post-test, 2- and 4-month follow-up and his scores were 13, 12, and 14, respectively.

According to the Family Quality of Life (QOL) Questionnaire (Feldman et al., 2002), Jake's mother rated the level of interference at 31.5 at pre-test and 16 at post-test, a 49% decrease. As described earlier, the QOL Questionnaire measures the level of interference that OCD is causing the family and child in a variety of settings and situations. For example, it asks how much interference OCD causes to the child's learning and the family's opportunities to attend social functions outside the home (See Appendix D). The consumer satisfaction questionnaire completed at post-test by Jake's mother also indicated high satisfaction with the treatment. In particular, Jake's mother rated the service her son received as maximally valuable and effective. Following treatment, Jake remarked "you guys really helped me." His mother and grandmother both echoed this statement saying "the changes we have seen in him are incredible; there are so many things he can do now that he couldn't before."

#### *Visual Inspection of Mary's Parent-Report Data*

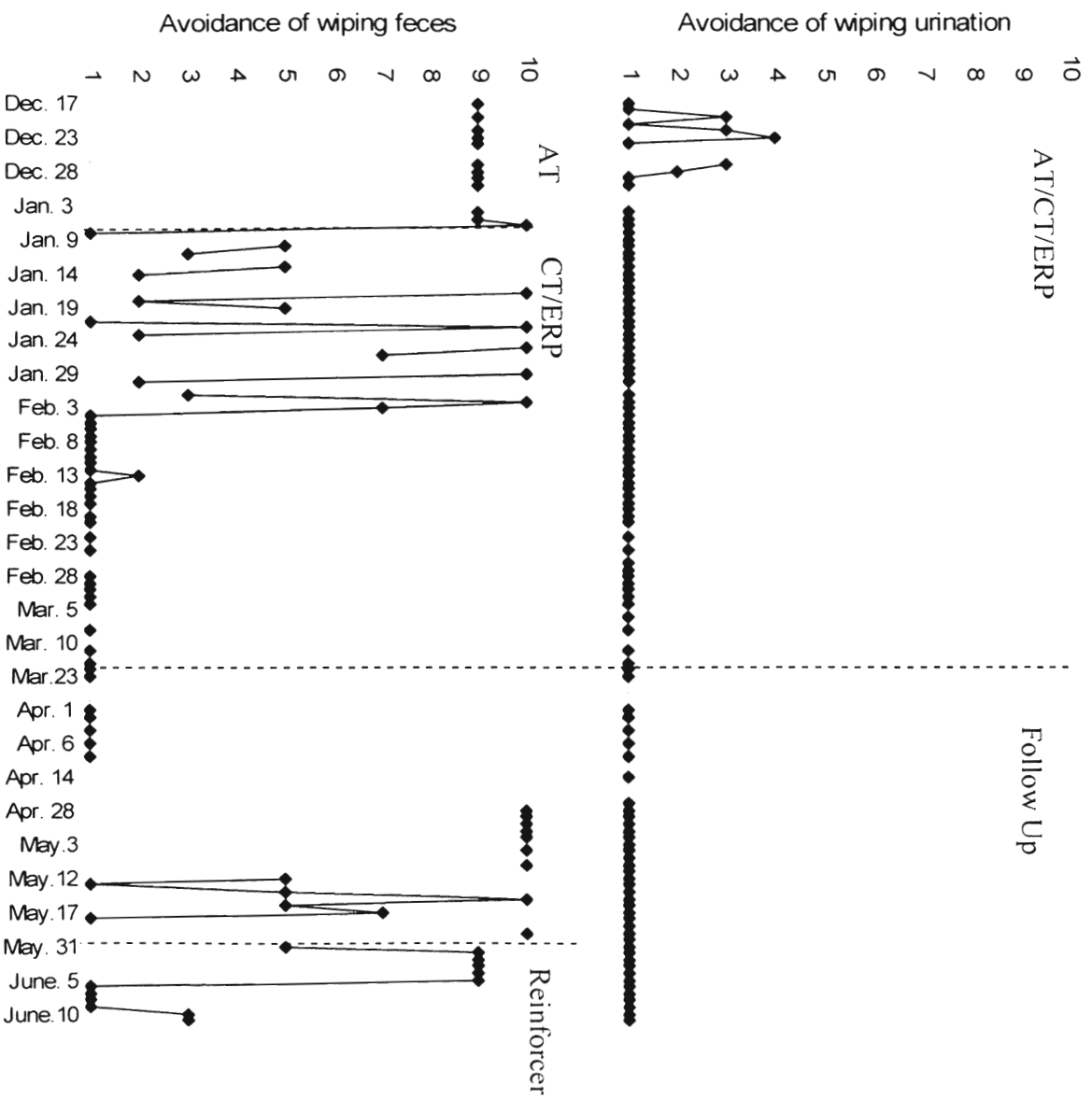
Mary's parent-report data showed similar results to Jake, as clinically significant decreases were seen for each of the specifically targeted behaviours when CT and ERP were applied.

*Avoidance of wiping.* See Figure 3 for Mary's avoidance of wiping urine and wiping feces. The baseline data for this behaviour is not presented as Mary's mother was originally asked to rate wiping urine and wiping feces as one behaviour, and only the former behaviour (i.e., wiping) decreased during baseline. The data presented begins at the point where Mary's mother began to rate each behaviour separately. Treatment began for wiping urine while Mary's mother continued to assist with wiping feces. Mary's mother responded to the question: "how much did Mary avoid wiping herself after using the bathroom?" and we asked her to consider wiping urine and wiping feces separately. This was rated on a scale of 1 (*not at all*), implying that Mary wiped completely independently to 10 (*very, very much*), meaning that she required complete assistance to wipe. In the top graph of Figure 3, it was evident that within 2 weeks of treating Mary's avoidance of wiping urine, the behaviour had decreased to zero-levels

At this point, CT and ERP commenced for wiping feces, which had remained high and stable during AT and the treatment of wiping urine. When CT and ERP were applied to wiping feces, the parent-ratings became variable, ranging from one to ten, with an average rating of 5.28 meaning that Mary was independently wiping feces less than 50% of the time. After 4 weeks, Mary was independently wiping both urine and feces. When treatment was applied to wiping feces, wiping urine remained at zero-levels. The first behaviour remaining stable offers possible control for wiping feces. It was hypothesized that because these behaviours were maintained by the same thought (i.e., contamination) that we would see a spike in wiping urine when treatment was applied to a similar behaviour. However, wiping urine remained stable at zero-levels while wiping feces became variable and after 4 weeks of CT and ERP decreased to zero-levels, offering further confidence that the treatment package was responsible for the treatment effect (Hayes, Barlow & Nelson-Gray, 1999).



Figure 3. Results for Mary's compulsive avoidance of wiping.

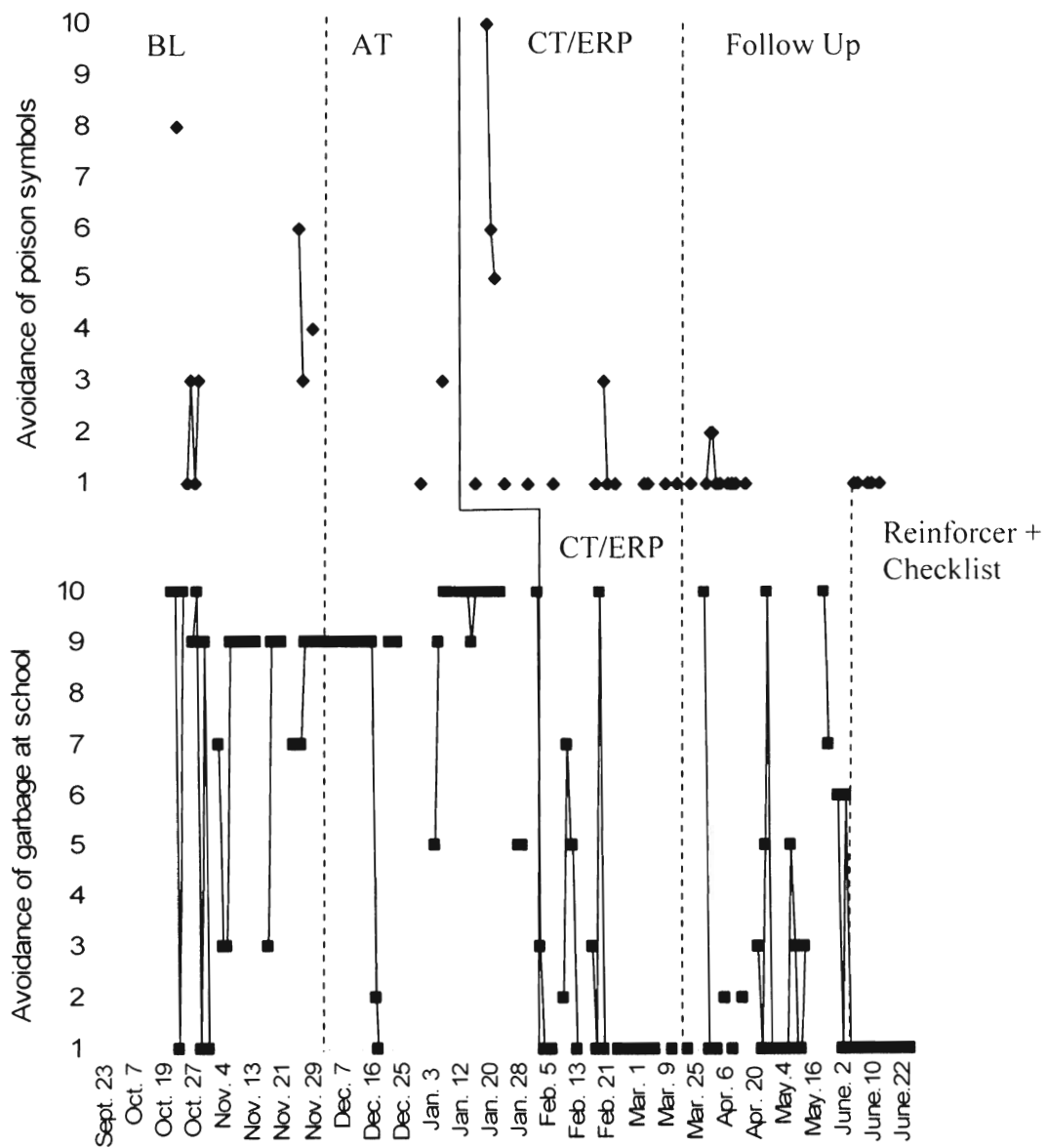


In follow-up, a relapse occurred in Mary's avoidance of wiping feces following 4 months at zero levels. At this point, Mary's mother reinstated strategies learned in session such as the self-monitoring checklist and added a reinforcement procedure where Mary would receive highly preferred tangibles for independently wiping each week. When these strategies were reintroduced, the behaviour became variable ranging from one to 10, with an average rating of 4.4 and then returned to zero-levels. We are continuing to monitor this behaviour and work with the family to keep it maintained at low levels.

*Avoidance of poison symbols.* See Figure 4 for the parent-ratings of Mary's compulsive avoidance of items with poison symbols and the garbage can at school. In the top graph of Figure 4, see parent ratings regarding the question: "How much did Mary avoid something because of a poison symbol?" This was rated on a scale of 1 (*not at all*) to 10 (*very, very much*). Given that Mary's compulsion was avoidance of the item, in baseline it was only possible for Mary's mother to collect data when Mary told her that she was avoiding something or if a natural situation arose where she observed her avoiding contact with an item with a poison symbol. Therefore, the data presented is likely an underestimation of the actual time Mary spent avoiding items with poison symbols. Nevertheless, Mary's mother's ratings of avoidance were variable and often higher during baseline than throughout treatment. During CT and ERP, contrived exposure situations were rated and appeared to be highly anxiety-provoking in the beginning but with repeated exposures to various items, within 1-month, Mary's anxiety was brought to zero-levels on several different items. Low-levels of avoidance were maintained at 3-month follow-up.

*Avoidance of garbage.* In the second graph of Figure 4, see parent ratings regarding the question: "How much of her lunch did Mary bring home to avoid the garbage at school?" This

Figure 4. Results for Mary's compulsive avoidance of poison symbols and garbage can at school.

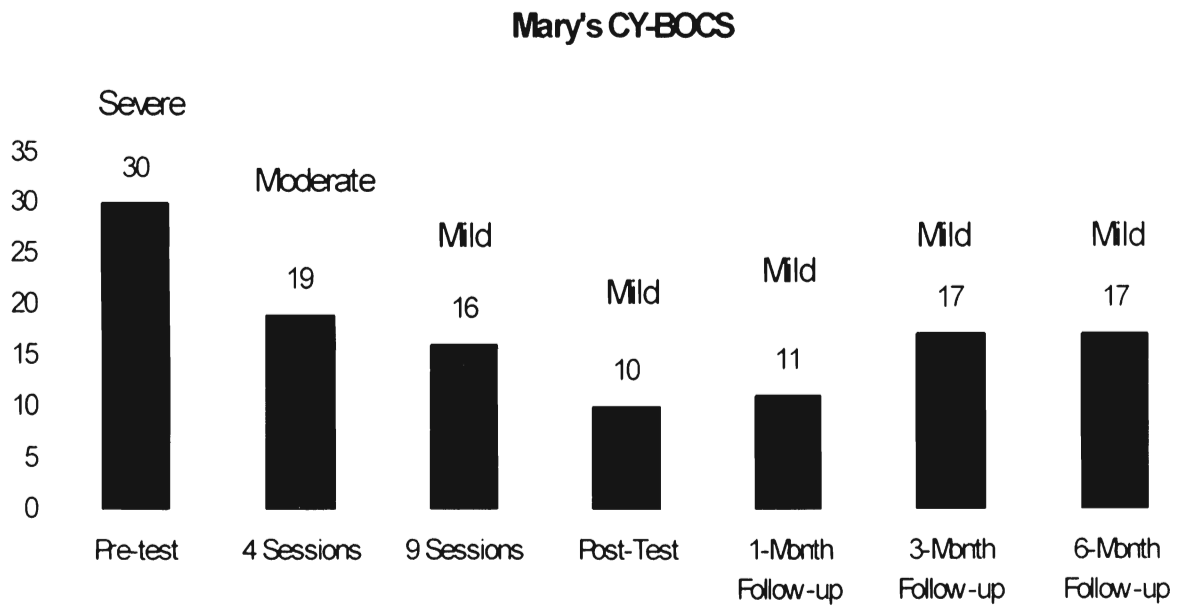


was rated on a scale of 1 (*none*) to 10 (*very, very much*). In baseline, this behaviour was variable but often high, indicating that most garbage items were being brought home. Out of 31 baseline days, there were only three days where no garbage was brought home. In these cases, we cannot be sure where Mary threw the garbage out, but her mother rated that no garbage came home. In AT, the behaviour remained high but variable, ranging from one to ten, with an average of 8.36 over 2 months. When CT and ERP were applied to this behaviour, it remained variable but lower for 2 weeks and then decreased to zero levels and remained stable for 1-month. During follow-up, the behaviour reoccurred at the same time as avoidance of wiping feces. Similarly, when this occurred, Mary's mother reinstated the checklist for throwing garbage out at school as well as offered Mary a strong tangible reinforcer for using the garbage can at school. When we met with Mary's mother, we encouraged her to continue having her daughter throw out all garbage brought home as well as revisiting coping statements and using the stimulus map at home. Following this, the behaviour again has decreased to zero-levels for 1-week and we are continuing to monitor it.

#### *Results of ADIS, CY-BOCS and Secondary Outcome Measures*

At post-test, assessment results suggested that Mary's OCD behaviours had decreased substantially. According to the ADIS (Silverman & Albano, 1996), Mary no longer met criteria for OCD. Similar to Jake, Mary's CY-BOCS scores decreased with the use of CBT. See Figure 5 for Mary's CY-BOCS scores. Mary's CY-BOCS scores decreased from 30, indicating severe OCD to 10 at post-test, a 67% decrease in symptoms indicating remission of OCD symptoms. At post-test, Mary's mother reported that when anxiety did occur, Mary was better equipped to manage it and it no longer interfered with the family's daily functioning. At 1-, 3-, and 6-month

Figure 5. Mary's CY-BOCS scores across treatment and QOL scores at pre- and post-test.



follow-ups, Mary's CY-BOCS scores as rated by her mother remained in the mild range at 11, 17 and 17, respectively.

According to the family of life measure, the level of family interference due to Mary's OCD decreased significantly at post-test. Mary's mother rated the level of interference as 28 at pre-test and 9 at post-test, representing a 68% decrease. Regarding consumer satisfaction, Mary's mother rated our therapy service on the Consumer Satisfaction Scale (Feldman et al., 2002) as maximally satisfying.

### Discussion

This single-case study with two school-age participants demonstrated that function-based CBT with parent involvement and use of behavioural supplements is a promising treatment package for OCD in children with HFA. Second, as hypothesized, an alleviation of OCD behaviours resulted in an increased quality of life for the children and their families. This study replicated the positive results of previous case studies ( $N = 1$ ) (Reaven & Hepburn, 2003; Lehmkuhl et al., 2008) that used the March and Mulle manual (1998) as a general framework. As well, similar results were reported in studies using a comparable CBT package (Sze & Wood, 2007; Wood et al., 2009). In replicating this work, we modified the treatment package to suit this dually diagnosed population. Key adaptations derived from previous studies included: (a) decreased emphasis on cognitive components, (b) active parent involvement, (c) child self-monitoring, and (d) the use of a token economy.

### *Similarities to Past Research*

A similarity to past studies (e.g. Reaven & Hepburn, 2003; Sze & Wood, 2007; Lehmkuhl et al., 2008) was a decreased emphasis placed on the cognitive components of the treatment package. Reaven and Hepburn reported that, given their participant's cognitive and

developmental level, a simple list of rules was more beneficial than using cognitive restructuring strategies. In addition, Lehmkuhl et al. reported protracting the cognitive component and starting ERP early. Similar to Reaven and Hepburn, their cognitive component included focusing on identifying feelings of distress and learning coping statements to alleviate anxiety. In the present study, the traditional cognitive components were attempted with both participants. For Jake, psychoeducation for finger smelling appeared useful. Also, he created several coping statements which appeared motivating initially but his mother reported that he did not use them in exposures unless prompted to do so. In Mary's case, she was even younger than Jake so it was not surprising that the traditional cognitive components of psychoeducation, restructuring and narrative therapy did not appear useful. However, Mary's mother did report that in natural situations, she often used coping statements that she had created in session. Similar to other studies, it was not possible to assess the effectiveness of CT for the participants; however at the very least, it appears that CT along with AT may provide the participants with simple statements that may help them resist engaging in compulsions.

The March and Mulle (1998) manual suggests treating the child individually, and including parents during short check-ins, and two sessions that focus on family therapy. In previous studies that have attempted to treat OCD in individuals with HFA (Reaven & Hepburn, 2003; Sze & Wood, 2007; Lehmkuhl et al., 2008; Wood et al., 2009), parents assumed an active role in treatment by being present for many sessions and providing information to the therapists regarding their child's OCD. For instance, Sze and Wood included an intensive parent training component that focussed on parenting skills, family communication, and the use of behavioural techniques to improve children's adaptive functioning.

Likewise, in this study, parents played an active role. Within session, they were instructed to act as coaches for their child. Parents were, at times, able to explain concepts in ways that were individualized to their children. They also facilitated rapport building with the therapists and aided in motivating their child to participate. Further, parents collected data and were responsible for carrying out elements of the treatment package within the home, such as contriving exposure tasks and prompting their child to use coping strategies. Having parents closely involved in the treatment appeared to facilitate a smooth generalization of the concepts learned in session to the home setting. In considering past studies as well as the current study, it appears that active parent involvement is an important enhancement to the delivery of psychosocial interventions for children with co-morbid PDD and anxiety.

In the present study, parents were often directly involved in the children's compulsions. For instance, Jake engaged in two behaviours that involved requesting his mother to smell his fingers and recite a bedtime ritual. Given that Jake relied on his mother to carry out his compulsions, we worked closely with the parent in gradually eliminating the compulsion, and were able to quickly reduce the behaviours to low levels. However, private behaviours such as Jake's soap digging and behaviours occurring outside the home setting, such as Mary's avoidance of the school garbage can appeared more resistant to the treatment package.

In addition to parent involvement, child self-monitoring was used and noted as beneficial (Reaven & Hepburn, 2003; Sze & Wood, 2007; Lehmkuhl et al., 2008). Self-monitoring was likely an important component included in the treatment package as it contributes to the development of self control (Martin & Pear, 2007). Martin and Pear discuss the use of self-monitoring as both a prompt to the individual to think about his or her progress as well as a prompt to receive extra social attention from others for completing the monitoring. For example,



Sze and Wood used a simple self-monitoring technique where the participant wore 10 bracelets and would transfer a bracelet from one wrist to the other whenever she “slipped up” by engaging in a compulsion. Similarly, in the present study, Jake was able to successfully monitor his completion of exposure tasks. Engagement in self-monitoring likely made Jake more aware of his compulsions, and was also linked to his backup reinforcers.

In Mary’s case, she engaged in self-monitoring of wiping by checking off specific written steps that were completed. Also, when treatment began on her avoidance of the garbage can, Mary and her mother began to track how many lunch items were discarded at school and how many were returned home. These checklists were brought into each session for the therapists to review. Similar to Jake, this allowed her to become more aware of the behaviour, and was motivating as she knew that if she could resist her compulsions for a number of days, she would be able to update her stimulus map when returning to session. Therefore, self-monitoring appeared to serve as another effective supplement to the March and Mulle (1998) treatment package.

Similar to past studies (e.g. Sze & Wood, 2007; Lehmkuhl et al., 2008), external reinforcement was beneficial in motivating the child to participate in ERP tasks. External reinforcement is considered a necessary component in most learning situations for children with autism (Maurice, Green & Luce, 1996). In the Sze and Wood study, a point system was devised to reward the participant for completing CBT homework tasks, where points could be exchanged for preferred activities. A similar system was utilized in the present study. For Jake and Mary, the use of a token economy motivated the children to meet treatment goals and engage in difficult exposure tasks to receive points, which could be traded in for preferred items or activities.

*Extensions of Past Research*

In extending past research, this study added several features to complement the collection of pre and post data. First, the use of a single-subject experimental design allowed for the systematic evaluation of the treatment response for each behaviour. The multiple baseline design across participants and behaviours offered experimental control that was not possible in previous studies (Cooper et al., 2007).

In addition to experimental control, having parents collect data on individual behaviours allowed the therapists to assess treatment effects for each behaviour. Visual inspection of the behaviours allowed us to assess even the slightest treatment responses. Further, when we observed that decreases in behaviours were not occurring for certain behaviours, it enabled us to troubleshoot and modify the treatment as necessary. This proved very important throughout treatment and in follow-up where brief relapses were experienced by both participants. Therefore, parent-report data on individual behaviours complemented the CY-BOCS and ADIS data that provided a general rating of OCD.

Second, the collection of extended follow-up data was carried out in this study. Past studies with this population included anecdotal reports that treatment gains were maintained or do not report on follow-up at all (e.g., Reaven & Hepburn, 2003; Sze & Wood, 2007; Wood et al., 2009). Similar to Lehmkuhl et al. (2008), 3 to 4-month follow-up has been collected. For a number of behaviours, we were able to demonstrate maintenance of behavioural change. When problems arose, we were able to help the parents address the issues immediately, and bring the behaviours back to low-levels.

Third, the inclusion of a comprehensive behavioural assessment was an important addition to this study. Previous studies treating OCD have not addressed the possible functions

maintaining the individual's compulsions, beyond anxiety reduction. In this study, the use of an indirect functional assessment aided in discovering perceived functions of the participants' compulsions as well as ruling out others. This was useful in providing some indication that anxiety reduction was the primary function of the behaviours for both children, as well as addressing other possible functions. For Jake, it was determined that physical ailments were likely to increase his reassurance seeking behaviours. With this information, it was possible to alert Jake's mother to watch for this antecedent and, in its presence, persist with treatment as well as lowering demands if necessary. The therapist was also able to address behaviours that were hypothesized as being, at least in part, attention- or escape-maintained.

Finally, the use of both a quality of life and consumer satisfaction questionnaire allowed the therapists to determine that this study had a high level of clinical significance for the two families. Both measures indicated that the families rated the treatment as valuable and that with successful treatment of OCD, the reported level of family interference declined. Baer, Wolf and Risley (1968) discuss the importance of assessing clinical significance in behavioural interventions. They remark that: "In evaluating whether a given application has produced enough of a behavioral change to deserve the label, a pertinent question can be, how much did that behavior need to be changed?" (Baer et al., p. 96). This is a practical question that was measured in this study using both a quality of life and a consumer satisfaction questionnaire. Jacobson and Truax (1991) describe achieving clinical significance as the extent to which therapy moves an individual outside the range of the dysfunctional population or within the range of the functional population. Using this definition, clinical significance was certainly achieved within this study as both participants moved from the severe to the mild range of OCD according to the CY-BOCS.

#### *Alternative Explanations of Findings*

It is important to acknowledge that there may be alternative explanations for results obtained in the current study. Similar to previous studies, we attributed treatment gains to the use of a multi-component CBT treatment package. However, one may question whether it was an individual component or the full treatment package that was responsible for the alleviation of OCD behaviours. As well, it is important to consider the behavioural supplements and modifications made to the treatment package. Finally, response generalization may have affected study outcomes.

Regarding the multiple components of the package, future studies may use component analyses to systematically evaluate the effectiveness of individual components on OCD behaviours. In the current study, it did not appear that AT alone had any effect on the behaviours. Treatment effects were evident when CT and ERP were simultaneously introduced but it is possible that these effects would not have been achievable without the inclusion of AT. Also, it is likely that the components will show varying levels of success based on both the profile of the child and the types of behaviours exhibited by the child. Therefore, future studies are needed to investigate the effects of individual components with children who present with different profiles and a wide range of behaviours.

Second, future studies may attempt to tease apart the effects of the behavioural supplements that were used in conjunction with the treatment package. In this study, regarding Jake's soap digging, minimal behaviour changes were evident when CT and ERP were applied; however, when the token economy was added to the existing treatment package, the behaviour was reduced to near zero-levels. Similarly, with Mary, external reinforcement was introduced when a relapse occurred with her avoidance of wiping and using the garbage can at school. This external reinforcement appeared instrumental in motivating Mary to resume her exposure tasks

and an immediate reduction in both behaviours was reported. Future studies may investigate the individual treatment effects of behavioural supplements as it is not possible to tease apart the effects attributed to the behavioural supplements and those attributed to the treatment package.

Lastly, experiencing success with one behaviour may have aided in the treatment of subsequent behaviours. Specifically, it is possible that the children generalized what they learned for one behaviour to another behaviour. Response generalization was not explicitly measured within this study or in previous studies with this population. However, in the current study, Jake's mother reported that after experiencing success with a few behaviours, he remarked that he now understood that it was OCD causing him to worry about others. Likewise, Mary's mother reported that her daughter began using coping statements created to aid with her avoidance of wiping to help her alleviate anxiety about stimuli with poison symbols. Response generalization was a positive feature shown by both participants in this study, and future studies may attempt to explicitly measure it.

### *Limitations and Future Research*

Similar to past case studies, these findings are limited in terms of generalizability. Given this, it is not possible to determine the extent that the participant's personal characteristics, family and environment contributed to the positive outcomes observed in the study. To increase external validity, additional case studies as well as randomized control trials with sufficient power are needed.

A second limitation of the current study is that the assessors of the participant's OCD symptoms were not blind to the goals of the study. Therefore, this may have led to bias in assessment results. Future studies should employ professionals who are not involved in the study to perform all informant assessments with the participants and their parents.

Third, the lack of baseline data for some behaviours is an obvious limitation. For Jake, new behaviours arose after treatment had commenced and therefore, it was not possible to collect baseline data. Likewise, for Mary, baseline data was collected for her compulsive avoidance of wiping. However, the parent-report question combined both wiping urine and feces; this proved too broad as Mary started to wipe only urine independently and therefore, her mother began rating the combination of behaviours as steadily improving. When it was discovered that this rating was only representative of changes seen in wiping urine and that no change had occurred in wiping feces, we asked Mary's mother to rate these behaviours separately. Therefore, it is important to carefully monitor baseline data, and perhaps, initially, conduct brief check-ins with parents regarding the individual questions.

Fourth, we noted earlier that collecting parent-report data in the home setting was a strength. However, subjective report data has its limitations. First, parent ratings may drift as a result of knowing the intended outcome of the treatment. Further, anchors are provided for the parent to base their ratings on but an operational definition of what each rating represented was not developed. In future studies, researchers may attempt, where possible, to simultaneously collect objective and subjective data. In the current study, using an audiorecorder, objective data was collected for the length of Jake's bedtime ritual. Future studies may investigate the use of audiorecorders and other tools to record data if applicable. Second, researchers may also increase objectivity by measuring permanent products. For instance, regarding Jake's soap digging, it would have been beneficial to take weekly photos of the soap, and have naïve observers rate the degree of damage.

Fifth, as mentioned previously, the inclusion of an on-going comprehensive behavioural assessment aided in confirming escape from obsessions as the primary function of the children's

compulsions. An informant assessment such as the revised QABF allowed us to hypothesize the perceived functions of the behaviours. However, it was not possible to determine the causes of the behaviours. In this study, the nature of the participants' compulsions precluded the collection of ongoing descriptive data or functional analogue assessments (Thompson & Iwata, 2007). For instance, both participants engaged in private behaviours, and behaviours outside of the home where it was not possible to observe them. Future studies may consider using these analyses if the behaviours are displayed in public and situations can be contrived to evoke them.

Also, studies indicate that the QABF has appropriate psychometric properties when utilized with individuals with intellectual disabilities (Matson et al., 1999). However, the measure has not been validated with children with PDD. Future studies are needed to investigate the validity and reliability of the QABF with this population. As well, the psychometric properties of the revised QABF, with five questions added to capture escape from anxiety as a possible function needs to be investigated.

Finally, procedural reliability checks were employed in this study. This had been done in previous large scale studies (Wood et al., 2009) but not in the case studies completed with this population. This was an important addition to the current study as including treatment integrity checks allowed us to ensure that the essential components suggested by March and Mulle (1998) were being carried out in treatment. Future research should also attempt, where applicable, to collect inter-observer and procedural reliability on OCD behaviours observed in the home setting. This may be accomplished by a therapist visiting the home and collecting data alongside a parent, both parents collecting data or a parent and child simultaneously monitoring the behaviour.

### *Implications of Research*

This research provides additional evidence towards validating an adapted CBT treatment for OCD in children and youth with HFA. Specifically, it adds to the promising results reported in past case studies, (Reaven & Hepburn, 2003; Sze & Wood, 2007; Lehmkuhl et al., 2008) and one RCT with eight participants with OCD (Wood et al., 2009). Information derived from CBT studies conducted thus far can be used to inform component analyses and randomized controlled trials. RCTs will likely lead to the development of an evidenced-based treatment for OCD for children with HFA. Additional research is needed to validate treatments for individuals who present with other anxiety disorders and varying autism phenotypes. Overall, this research provided training opportunities for undergraduate and graduate students at Brock University and helped to increase the awareness of and interest in the topic.

### Conclusion

This study showed promising results for the use of function-based CBT to treat OCD in two school age children with HFA. In this study, for both children, awareness training alone did not appear to have an effect on the OC behaviours, however the collective presentation of awareness training, cognitive training, exposure and response prevention, reinforcement and function-based behavioural strategies resulted in decreased engagement in compulsions for both children. In addition, an alleviation of OC behaviours resulted in an increase in parent-reported quality of life and parents indicated that they were very satisfied with the services provided. As well, 3 to 4 month follow-up data are currently available, and the majority of treated behaviours have remained at low levels. Across studies, given participants' cognitive and developmental levels, it was evident that the cognitive component of the treatment package needed to be modified. Second, active parent involvement appeared to enhance treatment, as parents were able to aid their children in understanding and "bossing back" OCD. A unique contribution of this



study was the inclusion of a comprehensive behavioural assessment which allowed the therapists to identify perceived functions of the behaviours and address them throughout treatment. Future research should include single-case studies as well as larger scale investigations are necessary to develop evidence-based treatments for this under-served population. Manualized treatment would help to operationalize treatment delivery and augment efforts to deliver such treatments to a broader base of community professionals and allow for enhanced collection of data in order to determine treatment effectiveness.

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## Appendix A – Ethics

## Consent Form:

Research Project Title: **Pilot Studies: Treating Obsessive-Compulsive Disorder in Children with High Functioning Autism and Asperger's Syndrome: Cognitive-Behavioral Treatment with Function-Based Intervention**

Principal Investigator: Dr. Tricia Vause (Brock University)

Co-Investigator: Dr. Maurice Feldman (Brock University)

Sponsor of Research: Brock University

\*This research is supported an initiative awarded from The Provincial Centre of Excellence for Child and Youth Mental Health at The Children's Hospital of Eastern Ontario.

This description, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

### What is the purpose of the study?

For children with High Functioning Autism (HFA) or Asperger's syndrome (AS) who also have a diagnosis of Obsessive Compulsive Disorder (OCD), we are interested in understanding more about what types of treatment techniques are helpful in reducing OCD symptoms. We are interested in testing out a combination of behavioral and cognitive-behavioral assessment and treatment methods that have been effective in treating anxiety and behavioral issues in child populations, including children and youth with autism. Each child in the study will be provided with an individualized treatment program that is modified to take into account his or her unique profile/characteristics, and involves his or her parent(s) through all steps of the process. The protocol may prove to be useful in reducing OCD symptoms to manageable levels, and, in turn, improving both the child and parents' quality of life.

### What does the project consist of and how long will the study take?

If you give consent for your child to take part in this project, the primary researcher will:

- Meet with you and your child, and spend one or two 30 min sessions to develop rapport and get to know you
- Conduct indirect assessments (e.g., semi-structured interviews that provide us with information concerning your child's anxiety, a series of questionnaires such as a Quality of Life questionnaire) and direct assessments (e.g., assessing your child's verbal and nonverbal reasoning skills). The tests that involve yourself and your child will be conducted in order to gather information regarding diagnoses, intellectual, and adaptive functioning. You and your child will also be asked to keep a daily track of OCD symptoms that are identified and defined throughout the study.



- Schedule approximately one hour sessions at your convenience, once per week for a total of 12 to 20 sessions. The treatment protocol will involve the following components: (a) a general introduction to OCD using a neurobehavioral framework; (b) cognitive training; (c) mapping out OCD symptoms and gaining awareness of duration spent engaging in OCD behaviors; (d) creating a hierarchy of OCD behaviors; (e) use of exposure and response prevention (to which a large number of sessions are dedicated); and (d) relapse prevention and training for generalization. During the implementation of the protocol, a function-based assessment will be conducted for OCD behaviors, and interventions will be derived as appropriate and added to the ongoing CBT. Altogether, the study will take about 35 hours of you and your child's time.

### **What personal information of my child will be accessed by the research staff?**

The researcher will access (if applicable) the following information from each parent: the age, diagnosis, level of functioning, previous intellectual and adaptive behavior assessments, previous psychological assessments, and use of/change in medication.

### **Will my child's personal information be kept confidential?**

All information will be kept confidential and stored in a locked office. Only the research staff will have access. Any presentations, reports, or publications about the project will not contain any identifying information, unless you give permission to the researchers to show video clips of your child. The information will be kept indefinitely, and will only be used for educational purposes.

Videotaping of sessions will take place to ensure treatment integrity and for purposes of data collection. Videotapes will be viewed by project staff only, and will be kept in a locked office. On some occasions, research staff will observe the session through a one-way mirror, in order to observe the assessment and treatment, as well as to collect data in order to ensure that the treatment is being implemented accurately.

### **What are the risks and benefits in taking part in the study?**

Generally, the procedures used in this study present no risks to your child beyond what you might encounter in everyday activities. When certain procedures are introduced, it is possible that there may be a short-term increase in worry or stress. However, in the long-term, it has been shown that exposure to these procedures has led to a reduction in symptoms.

Participants will benefit directly in that we will determine what OCD symptoms your child presents with, and conduct an individualized assessment and intervention with the goal of symptom reduction, and an increase in quality of life for you and your family.

### **Will I receive the results of the study?**

If you wish to have a written description of the results, please check YES in the appropriate box at the end of this form and we will send you a summary of the purpose of the study, general findings, as well relevant information concerning your child within 3 months after the completion of the study.

**Is there any payment or cost for participating?**

No. There is no payment or cost for participating in this research project.

**Is participation voluntary?**

Participation is voluntary. Whether you give consent for your child to take part in the study will in no way affect any services that you or your child may be receiving now or in the future. Moreover, even after you give consent, you can stop any time and for any reason by simply calling the principal investigator listed at the end of the consent form.

Last, the cooperation of your child to continue in this study (e.g., their willingness to come with you to a session and to work with the research project staff) will be monitored throughout the study. If at any time your child does not want to participate, that decision will be respected and the session will be cancelled/rescheduled. If you feel that your child is unable to communicate this to us, we will rely on you to let us know if and when to stop the sessions. If this happens on a continual basis (e.g., several times in a row), we will accept this as a possible indication that your child does not wish to continue and will discontinue his or her participation from the project. Of course, we will discuss this with you before the decision is made.

**Will I be contacted in the future for other studies?**

The results of this research may lead to other related studies in the future that may be beneficial to your child. Please check the appropriate box at the end of this form if you would like to be contacted directly by the researchers in the future about other studies.

**Signing the Consent Form**

Signing the following page of this *Project Description and Consent Form* indicates that you have understood to your satisfaction the information regarding participation in the research project and agree for your child to participate. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. This study has received ethics clearance through REB file # 07-051. The Research Ethics Officer can be contacted at mailto: [reb@brocku.ca](mailto:reb@brocku.ca) or (905) 688-5550 ext. 3035, and can provide responses to questions about the research participant's rights.

**Principal Investigator:**

**Dr. Tricia Vause, Phone: (905) 688-5550, ext.3559**

**Signatures**

I \_\_\_\_\_, hereby:  
**(Parent/Guardian – please print your name)**

☐ consent to my participation and my child's participation in completing direct and indirect assessments.

☐ consent to \_\_\_\_\_'s participation in this study.  
**(please print child's name)**

By giving consent I allow the research project staff to:

- Work with me and my child in weekly one-hour sessions for 12 to 20 weeks.
- Conduct developmental and adaptive functioning assessments that involve me and my child.
- To obtain personal information, including: age, diagnosis, level of functioning, previous intellectual and adaptive behavior assessments, and previous psychological assessments.
- Videotape my child, in order to ensure treatment integrity, for purposes of data collection, and to show clips for educational purposes at talks and conferences for parents, students, and professionals. The raw footage of the videotapes will be viewed by project staff only, and will be kept in a locked office. The videos will be kept indefinitely, but will to be used for educational purposes only.
- Include my child's results in publications, reports, and talks, so that others may learn from this project.

I understand that I can revoke or amend this consent at any time and for any reason.  
 The consent will otherwise remain in effect for a period of 12 months from the date it is received.

<i>Please check YES or NO for the following items:</i>	YES	NO
• I would like to receive the results of this study.		
• I allow the researchers to share my child's results with authorized staff.		
• I allow the video clips of my child to be shown for educational purposes at talks and conferences (see above for details)		
• The researchers may contact me directly for possible future related studies.		

\_\_\_\_\_  
**Signature of Parent/Guardian**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Name of Researcher/Delegate**

\_\_\_\_\_  
**Signature of Researcher/Delegate**

\_\_\_\_\_  
**Date**

Please return all 4 pages of this *Project Description and Consent to Participation Form* in the enclosed stamped envelope to the principal investigator. Keep the extra copy for your records. Thank you for cooperation.

Assent Form:

Research Project Title: **Pilot Studies: Treating Obsessive-Compulsive Disorder in Children with High Functioning Autism and Asperger's Syndrome: Cognitive-Behavioral Treatment with Function-Based Intervention**

Principal Investigator: Dr. Tricia Vause, Ph.D. (Brock University)

Co-Investigator: Dr. Maurice Feldman, Ph.D. (Brock University)

Sponsor of Research: Brock University

\*This research is supported an initiative awarded from The Provincial Centre of Excellence for Child and Youth Mental Health at The Children's Hospital of Eastern Ontario.

This description, a copy of which will be left with you, will tell you what the research is about if you decide that you would like to be part of it. If you have questions or would like more of an explanation about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this, and to understand any other information that is given to you.

### **What is the purpose of the study?**

We are interested in understanding more about what types of treatments might be helpful in reducing your worries, uncomfortable thoughts, or behaviors that you feel that you have to do. We are interested in testing out a combination of different methods that have helped in treating worries, thoughts that bother you, etc. You will be provided with a treatment program that takes into account your needs, and your parent(s) will be involved throughout all steps of the process. The protocol may prove to be useful in reducing thoughts and things you feel that you have to do that may bother you, and, in turn, improving both you and your family's quality of life.

### **What does the project consist of and how long will the study take?**

If you decide you would like to take part in this project, the primary researcher will:

- Meet with you and at least one parent, and spend one or two 30 minutes meetings getting to know you and your parent(s)
- Ask you questions about your life and about your fears, worries or behaviors that you feel you have to do. These questions will be asked in order to better understand how we can help you. Also you and your parent will be asked to keep a daily track of worries and behaviors that you would like to stop doing. These thoughts and behaviors will be recorded and tracked throughout the entire study.
- Schedule one hour sessions at you and your parent's convenience, once or twice per week for a total of 12 to 20 sessions. These sessions will involve the following: (a) exploring how the worries and thoughts you have can be examined through a biological framework; (b) helping you change your thoughts and worries by teaching you ways to "talk back" to OCD (c) tracking your worries and behaviors and gaining awareness of the time spent engaging in these behaviors; (d) creating a list of fears and behaviors and listing them in terms of how much fear they make you feel (e) exposing you to feared objects and teaching

you ways to help reduce the fear (f) helping you worries to stay out of your life for good, in all areas of your life including home, school etc.,  
 Throughout our time spent together you will be asked to track your thoughts, worries, feelings and behaviors on a sheet. This will help to address your unique needs.  
 Altogether, we estimate the study will take about 35 hours of you and your parent's time.

### **What personal information of mine will be accessed by the research staff?**

The researcher will access (if applicable) the following information: your age, diagnosis, previous assessments related to how you are doing in general (in school, home, etc.), and use or/change in medication.

### **Will my personal information be kept confidential?**

All information will be kept private and stored in a locked office. Only the research staff will have access to your personal information.

Videotaping of sessions will take place to ensure everything is running smoothly and to see if you are in fact benefiting from the treatment. Videotapes will be viewed by project staff only, and will be kept in a locked office. Any presentations, reports, or publications about the project will not contain any identifying information, unless you give permission to the researchers to show video clips of you. The information will be kept indefinitely, and will only be used for educational purposes.

On some occasions, research staff will observe the session through a one-way mirror, in order to observe the assessment and treatment, as well as to collect data in order to ensure that the treatment is being implemented accurately.

### **What are the risks and benefits in taking part in the study?**

Generally, the procedures used in this study present no risks to you beyond what you might encounter in everyday activities. When certain procedures are introduced, it is possible that there may be a short-term increase in worry or stress. However, in the long-term, it has been shown that exposure to these procedures has led to a reduction in worries.

You will benefit directly from this study in that we will determine what worries/thoughts and bothersome behaviors are present, and will teach you ways to “beat” or “fight back” OCD. In the end, we hope you will be better able to manage your worries, feelings and behaviors which will hopefully make things easier on you and your family.

### **Will I receive the results of the study?**

If you wish to have a written description of the results, please check YES in the appropriate box at the end of this form and we will send you a summary of the purpose of the study, general findings, as well relevant information concerning your individual performance within 3 months after the completion of the study.

**Is there any payment or cost for participating?**

No. There is no payment or cost for participating in this research project.

**Is participation voluntary?**

Participation is voluntary. Whether you agree to take part in the study will in no way affect any services that you may be receiving now or in the future. Moreover, even after you give consent, you can stop any time and for any reason by simply calling the principal investigator listed at the end of the consent form.

Last, if at any time during the study you do not want to participate, that decision will be respected and the session will be cancelled/rescheduled. If this happens on a continual basis (e.g., several times in a row), we will accept this as a possible indication that you do not wish to continue and will discontinue participation in the project. Of course, we will discuss this with you before the decision is made.

**Will I be contacted in the future for other studies?**

The results of this research may lead to other related studies in the future that may be beneficial to you. Please check the appropriate box at the end of this form if you would like to be contacted directly by the researchers in the future about other studies.

**Signing the Consent Form**

Signing the following page of this *Project Description and Consent Form* indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. This study has received ethics clearance through REB file #07-051. The Research Ethics Officer can be contacted at mailto: [reb@brocku.ca](mailto:reb@brocku.ca) or (905) 688-5550 ext. 3035, and can provide responses to questions about the research participant's rights.

**Principal Investigator:**

**Dr. Tricia Vause, Phone: (905) 688-5550, ext.3559**

**Signatures**

I \_\_\_\_\_, hereby:

(Child's name)

☐ assent to my participation in completing direct and indirect assessments.

By giving assent I allow the research project staff to:

- Work with me and my parent in weekly one-hour sessions for 12 to 20 weeks.
- Conduct developmental and adaptive functioning assessments that involve me and my parent.
- To obtain personal information, including: age, diagnosis, previous intellectual and adaptive behavior assessments, and previous psychological assessments.
- Videotape me, in order to ensure treatment integrity, for purposes of data collection, and to show clips for educational purposes at talks and conferences for parents, students, and professionals. The raw video footage will be viewed by project staff only, and will be kept in a locked office. The videos will be kept indefinitely to be used for educational purposes only.
- Include my results in publications, reports, and talks, so that others may learn from this project.

I understand that I can revoke or amend this assent at any time and for any reason. The assent will otherwise remain in effect for a period of 24 months from the date it is received.

<i>Please check YES or NO for the following items:</i>		YES	NO
• I would like to receive the results of this study.			
• I allow the researchers to share my results with authorized staff.			
• I allow the video clips of me to be shown for educational purposes at talks and conferences for parents, students and professionals.			
• The researchers may contact me directly for possible future related studies.			

_____ <b>Signature of Participant</b>		_____ <b>Date</b>	
_____ <b>Name of Researcher/Delegate</b>		_____ <b>Signature of Researcher/Delegate</b>	
		_____ <b>Date</b>	

Please return all 4 pages of this *Project Description and Consent to Participation Form* in the enclosed stamped envelope to the principal investigator. Keep the extra copy for your records. Thank you for cooperation.

## Appendix B – CY-BOCS

**Children’s Yale-Brown Obsessive Compulsive Scale (CY-BOCS)****DEFINE OBSESSIONS & COMPULSIONS**

Before proceeding with the questions, define “obsessions and compulsions for the child and primary caretaker as follows:

*Obsessions* are thoughts, ideas or pictures that keep coming into your mind even though you don’t want them to. They may be unpleasant, silly or embarrassing”

*Compulsions* are things you feel you have to do although you know that they do not make sense. Sometimes you may try to stop from doing them but this might not be possible.

**PROCEDURE**

*Symptom Checklist:* after reviewing obsessions and compulsions, the interviewer should get a detailed inquiry about the child’s obsessions and compulsions. This can be done by using the Compulsion Checklist and Obsession Checklist as a guide

*Target Symptom List:* after the compulsion checklist is complete, list the four most severe compulsions on the Target symptom list.

*Severity Rating:* inquire about the severity of items: Time Spent, Distress, Resistance, Interference, Degree of Control. Ratings for these items should reflect the interviewer’s best estimate from all available information from the past week, with a special emphasis on Target Symptoms.

Scoring: all 19 items are rated but only 1-10 determine the total score



Target Symptom List for Obsessions

Obsessions (describe, listing by order of severity, with 1 being the most severe, 2 second most severe etc.,)

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

**QUESTIONS ON OBSESSIONS****1. Time Occupied by Obsessive Thoughts**

Question: *How much time do you spend thinking about these things? OR How frequently do these thoughts occur?*

<u>Time Spent on obsessions</u>	0	1	2	3	4
	None	Mild <1 hr a day	Moderate 1-3hrs	Severe >3 up to 8 hrs	Extreme >8hrs

**b. Obsession Free Interval (not scored)**

Question: *On average, what is the longest amount of time each day that you are not bothered by obsessive thoughts?*

<u>Obsessive Free Interval</u>	0	1	2	3	4
	None	Mild >8 hrs	Moderate 3-8 hrs	Severe 1-3 hrs	Extreme <1 hr

**2. Interference due to Obsessive Thoughts**

Question: *How much do these thoughts get in the way of doing things with friends?  
Is there anything you don't do because of them?*

<u>Interference</u>	0	1	2	3	4
	None	Mild Slight interference	Moderate Definite interference but still manageable	Severe Substantial Impairment	Extreme Incapacitating

**3. Distress Associated with Obsessive Thoughts**

Question: *How much do these thoughts bother or upset you?*

<u>Distress</u>	0	1	2	3	4
	None	Mild infrequent. not to disturbing	Moderate frequent. disturbing manageable	Severe very frequent & disturbing	Profound Near constant. disabling

**4. Resistance to Obsessions**

Question: *How hard to you try to stop the thoughts or ignore them?*

<u>Resistance</u>	0	1	2	3	4
	None	Mild Tries most of Time	Moderate Makes some effort	Severe Yields to all obsessions but is reluctant	Profound Completely & willingly yield to all obsessions

**5. Degree of Control over Obsessive Thoughts**

Question: *When you try to fight the thoughts can you beat them?*  
*How much control do you have over the thoughts?*

<u>Degree of Control</u>	0	1	2	3	4
	Complete Control	Much Control	Moderate Control	Little Control	No Control

**Target Symptom List for Compulsions**

Compulsions (describe, listing by order of severity, with 1 being the most severe, 2 second most severe etc.,)

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

**QUESTIONS ON COMPULSIONS****6. Time Spent Performing Compulsion**

Question: *How much time do you spend doing these things? OR How much longer than most people does it take to complete your usual daily activities because of these habits?*

<u>Time Spent</u>	0	1	2	3	4
	None	Mild <1 hr a day	Moderate 1-3hrs	Severe >3 up to 8 hrs	Extreme >8hrs

**6b. Compulsion Free Interval (not scored)**

Question: *How long can you go without performing compulsive behaviour?*

<u>Obsessive Free Interval</u>	0	1	2	3	4
	None	Mild >8 hrs	Moderate 3-8 hrs	Severe 1-3 hrs	Extreme <1 hr

**7. Interference due to Compulsive Behaviours**

Question: *How much do these habits get in the way of doing things with friends?*  
*Is there anything you don't do because of them?*

<u>Interference</u>	0	1	2	3	4
	None	Mild Slight interference	Moderate Definite interference but still manageable	Severe Substantial Impairment	Extreme Incapacitating

**8. Distress Associated with Compulsive Behaviours**

Question: *How upset would you feel if prevented from carrying out your habits?*  
*How upset would you become?*

<u>Distress</u>	0	1	2	3	4
	None	Mild Only slight Anxiety	Moderate Anxiety but manageable	Severe Disturbing Increase anxiety	Profound Incapacitating

**9. Resistance against Compulsions**

Question: *How much do you try to fight the habits?*

<u>Resistance</u>	0	1	2	3	4
	None	Mild Tries most of Time	Moderate Makes some effort	Severe Yields to all habits but is reluctant	Profound Completely & willingly yield to all habits

**10. Degree of Control over Compulsive Behaviour**

Question: *How strong is the feeling that you have to carry out the habit?*  
*When you try to fight them, what happens?*  
*How much control do you have over the behaviours?*

<u>Degree of Control</u>	0	1	2	3	4
	Complete Control	Much Control	Moderate Control	Little Control	No Control

**11. Insight Into Obsessions and Compulsions**

Question: *Do you think your concern or behaviours are reasonable?*  
*What do you think would happen if you did not perform the compulsions?*  
*Are you convinced that something would really happen?*

<u>Insight</u>	0	1	2	3	4
	Excellent Insight Rational	Good insight but isn't completely Convinced	Fair insight, recognizes unreasonable not convinced	Poor insight, not unreasonable	Lacks insight behaviour is reasonable

**12. Avoidance**

Question: *Have you been avoiding doing anything, going any place, or being with anyone because of your obsessional thoughts or out of concern you will perform a compulsion?*

*How much do you avoid?*

<u>Avoidance</u>	0	1	2	3	4
	None	Minimal Avoidance	Moderate Some	Severe Much	Extreme Avoidance

**13. Degree of Indecisiveness**

Question: *Do you have trouble making decisions about little things that other people might not think twice about (e.g., which clothes to put on in the morning; which brand of cereal to buy?)*

Exclude: ruminating thinking, ambivalence concerning rationally based difficult choices

<u>Indecisiveness</u>	0	1	2	3	4
	None	Mild Some trouble but Minor	Moderate reports trouble	Severe Continually weighs pros/cons	Extreme Unable to make decision

**14. Over-valued sense of Responsibility**

Question: *Do you feel overly responsible for what you do and for the effects of your actions? Do you blame yourself for things that are not within your control?*

<u>Responsibility</u>	0	1	2	3	4
	None	Mild Only mentioned Upon questioning	Moderate over-responsibility for events out of control	Severe deeply concerned responsible for events	Extreme delusional sense of responsibility

**15. Pervasive Slowness/Disturbance of Inertia**

Question: *Do you have difficulty starting or finishing tasks? Do many routine activities take longer than they should?*

<u>Slowness</u>	0	1	2	3	4
	None	Mild Delay	Moderate task usually Completed but late	Severe marked difficulty completing tasks	Extreme unable to start & complete tasks without assistance

**16. Pathological Doubting**

Question: *After you complete an activity do you doubt whether you performed it correctly? Do you doubt whether you did it at all?*

*When carrying out routines do you find that you don't trust your senses (i.e., what you see, hear or touch?)*

<u>Doubting</u>	0	1	2	3	4
	None	Mild	Moderate	Severe	Extreme

Only mentioned      clearly present      doubt effects      incapacitating  
when questioned      but manageable      performance

### 17. Global Severity

*Interviewers judgement of the overall severity of the patient's illness (consider the degree of distress reported by the patient, the symptoms observed and the functional impairment reported)*

0	1	2	3	4	5	6
No illness	Slight No functional Impairment	Mild little functional Impairment	Moderate functions with effort	Moderate-Severe Limited functioning	Severe functions mainly with assistance	Extremely severe completely non functional

### 18. Global Improvement

*Rate total overall improvement present since the initial rating whether or not in your judgement is due to treatment.*

0	1	2	3	4	5	6
Very much Worse	Much worse	Minimally Worse	No Change	Minimally Improved	Much Improved	Very much Improved

### 19. Reliability

*Rate the overall reliability of the rating scores obtained. Factors that may affect reliability include the patient's cooperativeness and his or her natural ability to communicate. The type and severity of the obsessive compulsive symptoms present may interfere with the patient's ability to concentration, attentions, or freedom to speak spontaneously (e.g., the content of some obsessions may cause the patient to choose his words very carefully)*

0	1	2	3
Excellent No reason to Suspect Unreliable	good factors present may adversely affect reliability	Fair factors present definitely reduce reliability	Very Low reliability

## Appendix C – Revised QABF

**QUESTIONS ABOUT BEHAVIORAL FUNCTION (QABF)**

Child's name: \_\_\_\_\_

Name of the person completing the QABF \_\_\_\_\_ Date: \_\_\_\_\_

Target Behaviour: \_\_\_\_\_

*Rate how often the child demonstrates the behaviours in situations where they might occur.**Be sure to rate how often each behaviour occurs, not what you would think a good answer would be*

	N/A	Never (0)	Rarely (1)	Some (2)	Often (3)
1. Engages in the behaviour to get attention	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
2. Engages in the behaviour to escape work or learning situations	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
3. Engages in the behaviour as a form of "self stimulation"	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
4. Engages in the behavior because he/she is in pain	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
5. Engages in the behaviour to get access to items such as preferred toys, food or beverages	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
6. Does the person seem to engage in the behaviour to get rid of uncomfortable thoughts/images/impulses	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
7. Engages in behaviour because he/she likes to be reprimanded	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
8. Engages in the behaviour when asked to do something (i.e., get dressed, brush teeth, etc., )	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
9. Engages in the behaviour even if he/she thinks no one is in the room	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
10. Engages in the behaviour more frequently when he/she is ill	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
11. Engages in the behaviour when you take something away from him/her	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
12. Engage in the behaviour to reduce stress or prevent some dreaded situation from occurring (but the behaviour is not connected in a realistic way with that they are designed to neutralize	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
13. Engages in the behaviour to draw attention to him/her self	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
14. Engages in the behaviour when he/she does not want to do something	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
15. Engages in the behaviour because there is nothing else to do	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
16. Engages in the behavior when there is something bother him/her physically	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
17. Engages in the behavior when you have something	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

he/she wants					
18. Engages in the behaviour in response to a thought or according to a rule that must be applied rigidly					
19. Engages in the behavior to try to get a reaction from you					
20. Engages in the behaviour to try to get people to leave him/her alone					
21. Engages in the behaviour in a highly repetitive manner, ignoring his or her surroundings					
22. Engages in the behaviour because he/she is uncomfortable					
23. Engages in the behavior when a peer has something he/she wants					
24. Engages in the behaviour to cope with thoughts/images/impulses					
25. Does he/she seem to be saying "come see me" or "look at me" when engaging in the behaviour					
26. Does he/she seem to be saying "leave me alone" or "stop asking me to do this" when engaging in the behaviour					
27. Does he/she seem to be enjoying the behavior even if no one is around?					
28. Does the behaviour seem to indicate the his/she is not feelings well					
29. Does he she seem to be saying "give me that (item) when engaging in the behaviour?					
30. Does the child appear worried (i.e. facial expressions, body tightened) before engaging in the behaviour					

## Appendix D – Quality of Life

**Quality of Life Impact Questionnaire**

Name of Child: \_\_\_\_\_ Child DOB: \_\_\_\_\_

Name of Informant: \_\_\_\_\_ Relationship to Child: \_\_\_\_\_

Date: \_\_\_\_\_

Behaviour: \_\_\_\_\_

Please providing a rating for each question using the following rating scale:

1	2	3	4	5	6	7
minimally						extremely

- 
- \_\_\_\_ 1. Does the child's behaviour interfere with the child's opportunities for learning?
- \_\_\_\_ 2. Does the child's behaviour interfere with the child's opportunities for community integration or going out into the community?
- \_\_\_\_ 3. Does the child's behaviour interfere with the child's opportunities to develop friendships?
- \_\_\_\_ 4. Does the child's behaviour interfere with this child's opportunities to become involved in daily activities and routines?
- \_\_\_\_ 5. Does the child's behaviour interfere with opportunities of the family to invite friends into the home?
- \_\_\_\_ 6. Does the child's behaviour interfere with opportunities for family members to attend social functions and activities outside the home?
- \_\_\_\_ 7. Does the child's behaviour cause stress in others who live with the child?
- \_\_\_\_ 8. Does the child's behaviour result in others responding negatively to him/her?

TOTAL

---



## Appendix E – Consumer Satisfaction

**CONSUMER SATISFACTION QUESTIONNAIRE**

*Think about previous services you have received for you child's  
Obsessive and Compulsive Behaviours...*

---

Overall, how involved did you feel in the treatment?

1	2	3	4	5	6	7
						<i>very</i>
						<i>involved</i>

---

Overall, how satisfied were you in the services you received?

1	2	3	4	5	6	7
						<i>very</i>
						<i>satisfied</i>

---

Overall, did you feel your child developed good strategies to cope with his or her  
obsessive compulsive behaviours?

1	2	3	4	5	6	7
						<i>very much</i>

---

Overall, how effective did you feel the services were?

1	2	3	4	5	6	7
						<i>very</i>
						<i>effective</i>

---

## Operational definitions of targeted behaviours

### Jake

1. Digging his nails into bars of soap.  
Any instance of Jake's fingernails touching a bar of soap.
2. Requesting for his mother to smell his fingers  
Any instance where Jake verbally requests or places his fingers into his mother's face for her to smell them.
3. Bedtime ritual  
Any instance where Jake requests to hear the bedtime ritual or refuses to go to bed without hearing it.

### Mary

1. Compulsive avoidance of wiping  
Any instance where Mary refuses to wipe herself or asks someone else to clean her.
2. Compulsive avoidance of poison symbols  
Any instance where Mary refuses to touch an object or enter an area because of a poison symbol.
3. Compulsive avoidance of the garbage can at school  
Any instance where Mary brings home her garbage items rather than using the garbage at school.

## Appendix G – Parent-report data collection forms

## Check In

Date: \_\_\_\_\_

Informant: \_\_\_\_\_

Please note triggers whenever possible.

A trigger is any event, situation, setting, person present that may have brought on the behaviour

Trigger : \_\_\_\_\_

1. Overall, how much did J. have to re-write/erase letters or words he wrote?

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much
	<u>Notes:</u>									

Trigger : \_\_\_\_\_

2. Overall, how much did J. have to seek reassurance about weather-related safety?

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much
	<u>Notes:</u>									

3. Overall, how bothered did J. seem during the asking about safety? (visual signs of anxiety - tone of voice, facial expression)

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much

Trigger : \_\_\_\_\_

4. Overall, how much did J. have to seek reassurance about death or dehydration?

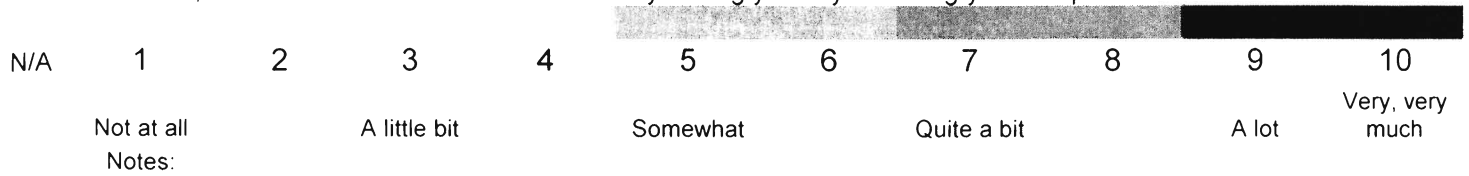
N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much
	<u>Notes:</u>									

5. Overall, how bothered did J. seem during the asking about death? (visual signs of anxiety - tone of voice, facial expression)

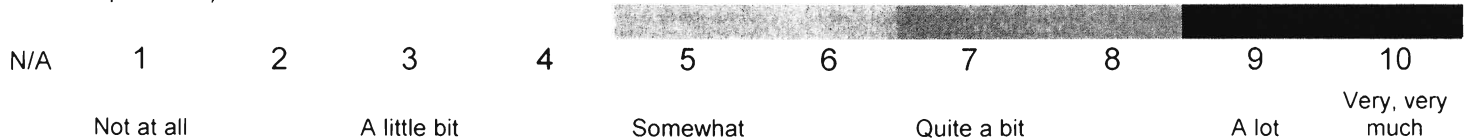
N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much

Trigger : \_\_\_\_\_

6. Overall, how much did J. seek reassurance by having you say or asking you to repeat the bedtime ritual?

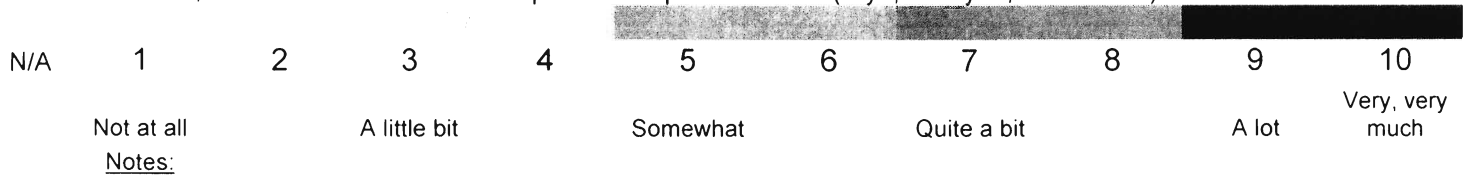


7. Overall, how bothered did J. seem during the bedtime ritual? (visual signs of anxiety - tone of voice, facial expression)

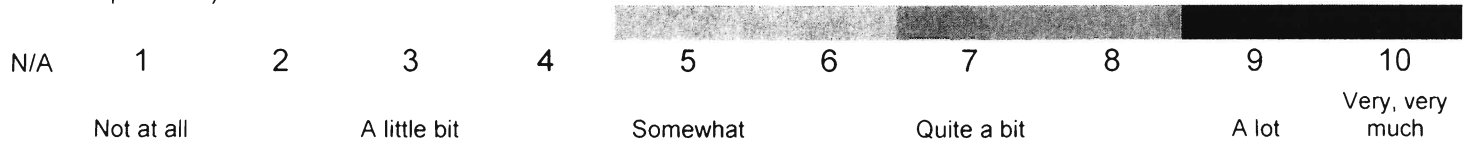


Trigger : \_\_\_\_\_

8. Overall, how much did J. have to repeat the separation ritual ("bye, love you, be careful")?

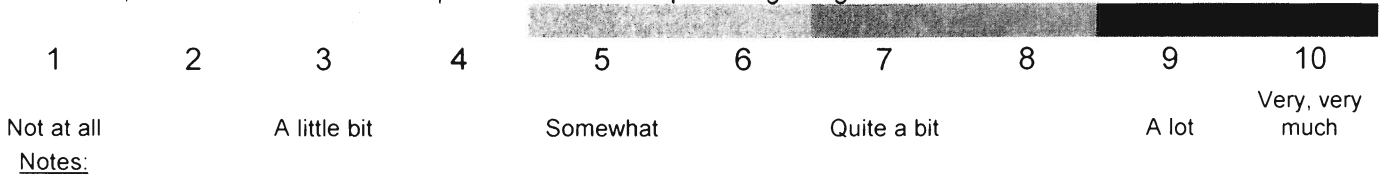


9. Overall, how bothered did J. seem when separating from mom? (visual signs of anxiety - tone of voice, facial expression)

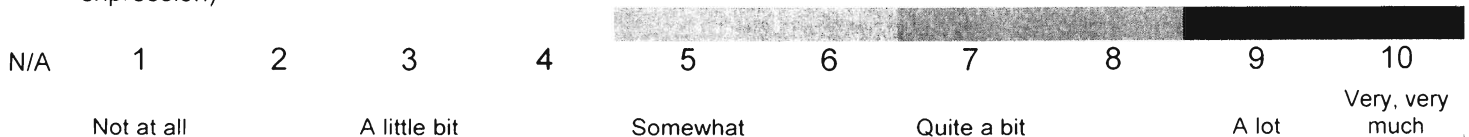


Trigger : \_\_\_\_\_

10. Overall, how much did J. have to put on his shoe to open the garbage can?



11. Overall, how bothered did J. seem when opening the garbage can? (visual signs of anxiety - tone of voice, facial expression)



Trigger : \_\_\_\_\_

12. Overall, how much did J. not eat his food because he was worried about "freshness"?

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much
	<u>Notes:</u>									

13. Overall, how much did J. have to dig his fingernails into bars of soap today?

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much

14. Overall, how much did J. have to have mom smell his fingers?

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much

Did J. dig his fingers into soap sometime today? (Please circle)

Yes                      No

Time of form completion: \_\_\_\_\_

Was the bedtime ritual recorded this evening? Yes    No

Was the morning/separation ritual recorded this morning? Yes    No

We welcome any anecdotal notes about Jake's Day!

## Check In

Date: \_\_\_\_\_

Informant: \_\_\_\_\_

Please note triggers whenever possible.

A trigger is any event, situation, setting, person present that may have brought on the behaviour

Trigger : \_\_\_\_\_

1. Overall, how much did M. engage in skin picking today?

N/A	1	2	3	4	5	6	7	8	9	10
			A little bit		Somewhat		Quite a bit		A lot	
	Not at all								Very, very much	

2. Overall, how bothered did M. seem when skin picking today (visual signs of anxiety - tone of voice, facial expression)?

N/A	1	2	3	4	5	6	7	8	9	10
			A little bit		Somewhat		Quite a bit		A lot	
	Not at all								Very, very much	

Notes:**\*for questions 3 and 4, please indicate separate ratings for number 1 and 2**

Trigger : \_\_\_\_\_

3. Overall, how much did M. avoid wiping herself after using the bathroom?

N/A	1	2	3	4	5	6	7	8	9	10
			A little bit		Somewhat		Quite a bit		A lot	
	Not at all								Very, very much	

4. Overall, how bothered did M. seem about having to wipe herself (visual signs of anxiety - tone of voice, facial expression) ?

N/A	1	2	3	4	5	6	7	8	9	10
			A little bit		Somewhat		Quite a bit		A lot	
	Not at all								Very, very much	

Notes:**\* Record (C) for a contrived situation with a poison symbol, record (N) for something natural that comes up.\***

Trigger : \_\_\_\_\_

5. Overall, how much did M. avoid something because of a poison symbol?

N/A	1	2	3	4	5	6	7	8	9	10
			A little bit		Somewhat		Quite a bit		A lot	
	Not at all								Very, very much	

Notes:

6. Overall, how bothered did M. seem when having to encounter a poison symbol (visual signs of anxiety - tone of voice, facial expression) ?

N/A	1	2	3	4	5	6	7	8	9	10
			A little bit		Somewhat		Quite a bit		A lot	
	Not at all								Very, very much	

## Specify (N) or (C) and what the item was

What? (shoes, seat, etc)

7. Overall, how much did M. avoid something because it was related to death?

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much

8. Overall, how bothered did M. seem about avoiding death-related items (visual signs of anxiety - tone of voice, facial expression) ?

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much

Notes:

Trigger : \_\_\_\_\_

9. Overall, how much of her lunch did M. bring home to avoid the garbage at school?

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much

Notes:

**\* Record (C) for a contrived situation with electricity, record (N) for something natural that comes up.\***

Trigger : \_\_\_\_\_

10. Overall, how much did M. avoid something because of fear of electricity?

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much

Notes:

11. Overall, how bothered did M. seem when having to encounter electricity (visual signs of anxiety - tone of voice, facial expression) ?

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much

12. Overall, how much did M. avoid going to the washroom because she was outside the home or mom wasn't around to wipe her?

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much

13. Overall, how bothered did M. seem when avoiding a public bathroom (holding it in)?

N/A	1	2	3	4	5	6	7	8	9	10
	Not at all		A little bit		Somewhat		Quite a bit		A lot	Very, very much

Did M. refuse to wear certain shoes today?  
(Please circle) Yes    No    N/A

Did M. bring home her garbage from her lunch?  
(Please circle) Yes    No    N/A

Did M. refuse to sit in a certain seat today?  
(Please circle) Yes    No    N/A

We welcome any anecdotal notes about M.'s Day!



## Appendix H – Treatment Integrity Checklist

**Treatment Integrity****Name of Observer:** \_\_\_\_\_**Date Reviewed Tapes:** \_\_\_\_\_**Date of Session:** \_\_\_\_\_**Behaviour:** \_\_\_\_\_**AWARENESS TRAINING**

N/A	YES	NO	Explained OCD as a problem that occurs in the brain (e.g. OCD is a brain hiccup) or is neurodevelopmental
N/A	YES	NO	Child shown diagram of brain
N/A	YES	NO	Explained OCD as something external to the child
N/A	YES	NO	Child drew picture of OCD and how much of life/time it takes up
N/A	YES	NO	Child explained picture to parent and therapists
N/A	YES	NO	Introduced the idea of “being the boss”
N/A	YES	NO	Child drew picture of his or her team or Allies
N/A	YES	NO	Child gave nickname to OCD
N/A	YES	NO	Introduced the idea of mapping different thoughts and behaviours of a child
N/A	YES	NO	Introduced the idea of transition or work zone
N/A	YES	NO	Discussed/mentioned fear thermometer
N/A	YES	NO	Explained “triggers” and tried to identify them
N/A	YES	NO	Child drew picture of his OCD worries
N/A	YES	NO	Introduced the idea of “tool kit”

**HOMEWORK**

N/A	YES	NO	Nickname for OCD
N/A	YES	NO	Map out when OCD wins
N/A	YES	NO	Parents review materials given
N/A	YES	NO	Parents stop providing OCD advice
N/A	YES	NO	Limit negative interactions by re-directing attention (DRO)

**COGNITIVE TRAINING**

N/A	YES	NO	Explain and create general coping statements (being boss)
N/A	YES	NO	Explain and create behaviour specific coping statements
N/A	YES	NO	Use psychoeducation and cognitive restructuring
N/A	YES	NO	Introduce and explain four steps involved in cultivating nonattachment
N/A	YES	NO	Discussed success and failures of Cognitive Training

**HOMEWORK**

N/A	YES	NO	Practicing coping statements at home
N/A	YES	NO	Continue paying attention to times OCD wins and child wins

N/A	YES	NO	Continue talking back/being boss of OCD
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### **E/RP TRAINING**

N/A	YES	NO	Explained E/RP
N/A	YES	NO	Review behaviour with parents and child
N/A	YES	NO	Discuss and modify treatment for behaviour based on child and parent information
N/A	YES	NO	Discuss thoughts associated with behaviour
N/A	YES	NO	E/RP trial exposure (if applicable)
N/A	YES	NO	Modify treatment program as necessary
N/A	YES	NO	Modify reinforcement protocol as necessary

### **HOMEWORK**

N/A	YES	NO	Practice exposures with thermometer (if applicable)
N/A	YES	NO	Continue practicing trial exposures for other behaviours

### **RELAPSE PREVENTION**

N/A	YES	NO	Explain concept of relapse prevention
N/A	YES	NO	Have child imagine an “expectable slip”
N/A	YES	NO	Have child explain what they would do if this or something new came up
N/A	YES	NO	Provide assistance with any remaining OCD behaviours

### **HOMEWORK**

N/A	YES	NO	Encourage child to practice exposure tasks (if applicable)
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### **GRADUATION**

N/A	YES	NO	Celebrate the child’s successes
N/A	YES	NO	Provide child with certificate for “being a good boss”
N/A	YES	NO	Address any of the parent’s concerns

### **ADAPTATION**

N/A	YES	NO	Identify and address functions (e.g., attention, sensory) as necessary
N/A	YES	NO	Decide new or unidentified ways of reinforcing functions of OCD (adaptation: add to cognitive training section)
N/A	YES	NO	Modify reinforcement protocol as necessary and gradually fade out (if applicable)